Health Information and Quality Authority
An tÚdarás Um Fhaisnéis agus Cáilíocht Sláinte

Health Information and Standards

Scoping review to inform standards for assessment of need

August 2024

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 the Minister for Children, Equality, Disability, Integration and Youth, 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 for more information.

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1. Introduction

1.1 Background

The Health Information and Quality Authority (HIQA) is the statutory body established under the Health Act 2007 to drive high-quality and safe care for people using health and social care services in Ireland. One of HIQA's many functions is to set standards for health and social care services.(1)

People with disabilities have a right to health and social care services that are focused on their needs and that work to meet these needs in a consistent and coordinated way. To do this, people's needs must be properly assessed, and the care and support they receive must be well planned, integrated, and tailored to their individual needs and circumstances.(2)

In Ireland, assessment of need is a statutory process under Part 2 of the Disability Act 2005.(3) An assessment of need is undertaken or arranged by the Health Service Executive (HSE) to determine the health or educational services required by a person who has a disability. Both the Disability Act 2005 and the Education for Persons with Special Educational Needs (EPSEN) Act 2004 set out that children and or young people born on or after 1 June 2002 with disabilities and or special educational needs are entitled to apply for an assessment of need.(3,4) The relevant section of the EPSEN Act has not yet been commenced, however a review of the EPSEN Act was conducted in 2022 by the Department of Education. The purpose of the review was to provide assurance that the law that governs the provision of education for children with special educational needs is adequate.(5) Further detail on the EPSEN Act can be found in Section 2.3.2.

The role of HIQA as set out under legislation in relation to assessment of need, is complex. Both the Disability Act 2005 and the EPSEN Act 2004 set out that assessment of need should be carried out under standards determined by HIQA.(3,4) HIQA is the authorised body in setting standards for assessment of need under the Disability Act.(3) However, the relevant section of the EPSEN Act has not been commenced, and so no obligations currently arise for HIQA in terms of setting standards for special educational need. In 2007, in advance of the establishment of HIQA, a cross-sectoral group established by the then Department of Health and Children and the Department of Education and Science developed and published *Standards for the Assessment of Need* (2007). These standards were then adopted by the Board of the interim Health Information and Quality Authority (iHIQA) and subsequently, by the HIQA Board.(6) As they were developed in 2007, these standards include out-of-date references and are not aligned with HIQA's current approach to development of national standards. To date, services undertaking assessment of need have not been monitored against these standards.

HIQA uses a prioritisation process for the development and updating of national standards for health and social care services.(7) In 2022, HIQA identified the *Standards for the Assessment of Need* as a priority for review, as there have been considerable changes in the health and social care landscape since they were developed in 2007 and the standards contain out-of-date references. Since this time, HIQA's standards development process has advanced to include a scoping review and consultation, a rigorous evidence review, public consultation and extensive stakeholder engagement.(8) Additionally, the current *Standards for Assessment of Need* are limited to the assessment of need process only. In line with international developments, the national standards developed by HIQA are now wider and are focused at a systems level.(9,10)

In order to understand developments in the area of assessment of need, HIQA undertook a scoping review. This scoping review examined assessment of need processes nationally and internationally to better understand the approaches and challenges to delivering an assessment of need service and to identify areas of good practice internationally. Further details on the research approach and the jurisdictions reviewed is set out in Section 1.4. The aim of this research is to inform next steps in relation to policy direction for assessment of need. This, in turn, will inform the need for national standards for this area, so that any standards developed have the maximum benefit for people with disabilities and their families.

The findings of this *Scoping review to inform standards for assessment of need* are summarised in a separate document, the *Executive summary of the scoping review to inform standards for assessment of need.* The executive summary provides an overview of the both the national and international systems for assessment of need, and sets out lessons to be learned and areas for consideration for Ireland from the approaches taken in other countries.

1.2 Standards development methodology and framework

HIQA follows a rigorous evidence-based methodology when developing any set of national standards.(8) The process involves a detailed evidence review and extensive stakeholder engagement. While the evidence review ensures that the standards are evidence-based, engagement with stakeholders, including people using services, ensures that the standards are appropriate to the Irish context, will improve the experience of people using services and can be implemented in practice.

National standards developed by HIQA are set out according to the principles outlined in the *Standards Development Framework: A principles-based approach* (2021).(10) These principles are:

- a human rights-based approach

- safety and wellbeing
- responsiveness, and
- accountability.(10)

The four principles are used as a framework throughout the development and updating of all national standards for health and social care services. National standards developed by HIQA are also outcomes focused, based on the outcomes that are important to people using the service.

1.3 Standards prioritisation process

HIQA operates a *Prioritisation Process for the Development of National Standards for Health and Social Care Services* (2020).(7) This process takes into account national policy and legislation as an integral part of the decision-making process. It ensures that HIQA develops standards that are of maximum benefit to the health and social care system. The process assists in identifying the priority areas for developing new and updated standards to reduce variation, improve safety and quality, and improve the outcomes of people using health and social care services. A programme advisory group for this process comprises key stakeholders from the Department of Health, the Department of Children, Disability, Equality and Integration and Youth (DCEDIY), Tusla, the Mental Health Commission, National Patient Forum, Health Service Executive and HIQA's Healthcare Regulation Directorate and the Chief Inspector of Social Services.

1.4 Methods

This report provides the results of a scoping review conducted to understand the organisation and delivery of assessment of need, which consists of:

1. **Assessment of need process in Ireland** - this includes a description of the current model and arrangements for assessment of need in Ireland, and an overview of legislation, standards, strategy, policy and frameworks currently in place. This research was informed by authoritative national websites, government reports, the findings of reviews conducted on the assessment of need process and outcomes, alongside engagement with subject matter experts in this area. This report describes the programme of delivery of assessment of need in Ireland including current challenges.
2. **A review of assessment of need processes internationally** — this includes a review of current processes in England, Scotland, Wales, Northern Ireland, Australia, New Zealand, Iceland, Romania, Hong Kong and Singapore. These 10 jurisdictions were selected based on the findings from a scoping review detailed in Section 3. A further desktop review of these

jurisdictions, involving web-based searches of relevant literature and websites, identified a number of key organisations and experts to contact and engage with. The review includes information from authoritative international websites, national reviews, reports from key organisations, and teleconferences with international subject matter experts in this area. The review describes the model of service delivery, relevant legislation, national policy, regulation and standards that support the assessment of need process in these jurisdictions.

1.5 Structure of this report

This document sets out the findings of the national and international research on assessment of need undertaken to inform the scoping review on the *Standards for the Assessment of Need* as follows:

Section 2: Assessment of need process in Ireland

Section 3: Approaches to assessment of need internationally

Section 4: Summary, conclusion and next steps.

2. Assessment of need process in Ireland

This section describes the organisation and delivery of assessment of need services in Ireland. The section is set out under the following headings:

- overview of assessment of need
- the model of service
- relevant legislation
- standards, guidance, frameworks, strategies and policies
- regulation and inspection of assessment of need
- findings from reviews
- summary.

2.1 Overview of assessment of need

In Ireland, assessment of need is a statutory process under Part 2 of the Disability Act 2005. An assessment of need is undertaken or arranged by the Health Service Executive (HSE), to determine the health or educational services required by a person who has disability. All children and or young people born on or after 1 June 2002 are eligible to apply for an assessment of need under the Disability Act 2005.(11) The Education for Persons with Special Educational Needs (EPSEN) Act 2004 established a statutory framework for the assessment of special educational needs and the development of individual education plans for children with such needs.(4) To date, key parts of the EPSEN Act that relate to a child's right to assessment and their education plans have not yet been commenced, which has led to a lack of clarity in relation to the assessment of education needs. Importantly, an assessment of need under the Disability Act is not necessary in order to access services, it is possible to get a direct referral to children's disability services or primary care services without an assessment of need and to directly access special education support.(12) In 2022, the population of Ireland was 5.1 million people, of which 1.1 million (22%) were reported to have a disability.(13,14)

Under the Disability Act 2005, HIQA is the authorised body in setting standards for assessment of need. In 2007, in advance of the establishment of HIQA, a cross-sectoral group established by the then Department of Health and Children and the Department of Education and Science developed *Standards for the Assessment of Need* (2007). These standards were adopted by the Board of the interim Health Information and Quality Authority (iHIQA) and subsequently, by the HIQA Board.(6) As they were developed in 2007, these standards include out-of-date references and are not aligned with HIQA's current approach to development of national standards.(8,10) To date, services undertaking assessment of need have not been monitored against these standards.

From June 2022 to June 2023, the HSE received 7,612 new applications for an assessment of need. This was an increase of over 20% on the number received in the previous 12 months. In addition to this, 11,430 assessments of need were overdue or had to be redone, resulting in a waiting list of 19,042 applications in 2023.(15) The Department of Health's *Disability Capacity Review to 2032 - A Review of Social Care Demand and Capacity Requirements to 2032* (2021) predicts that the combined impact of addressing unmet need and of demographic change will raise overall demand for therapy services by about two thirds by 2032.(16)

National reviews have been conducted by the National Disability Authority (NDA), the HSE, the Ombudsman for Children's Office (OCO) and the Joint Committee on Children, Equality, Disability, Integration and Youth.(17,18,19,20,21) These reviews have indicated that there are serious concerns regarding ongoing violations of the rights of children with disabilities and an over-reliance on diagnosis as opposed to needs.(17,19,20) More information on the findings from these reviews can be found in Section 2.6. At the time of writing (June 2024), the National Disability Authority (NDA) was conducting an independent review of the Children's Disability Network Team (CDNT) service model.(22)

In an effort to standardise and improve the assessment of need process, the HSE published an updated *Assessment of Need Standard Operating Procedure* (SOP) in 2023.(23) The purpose of this updated SOP is to ensure that there is a consistent approach to managing requests for a statutory assessment of need and processing the resulting referrals. The HSE's national programme 'Progressing Disability Services for Children & Young People' aims to ensure that services are provided equitably and consistently for all children. When the programme is completed, the aim is that there will be CDNTs across the country for all children with complex needs to access.(24) As part of this programme, the *Roadmap for Service Improvement 2023 – 2026: Disability Services for Children and Young People* (2023) is a targeted service improvement programme to achieve a quality, accessible, equitable and timely service for all children with complex needs as a result of a disability and their families.(15)

2.2 The model of service

This section describes the model for assessment of need in Ireland and is set out under the following sub-headings:

- structure and governance of assessment of need

- scope
- assessment of need process
- appeals process.

2.2.1 Structure and governance of assessment of need

A number of Government departments are responsible for the development of policy and overseeing the delivery of services for children and adults with disabilities. The Department of Children, Equality, Disability, Integration and Youth (DCEDIY) is responsible for child wellbeing, including the protection and welfare of children at risk or in the care of the State and specialist disability services for children and adults. These specialist disability services are provided by the HSE and a range of other providers to children and adults in residential, day and respite settings, as well as children's therapy services, personal assistance, home support and other community services and supports.(25) The Department of Health holds responsibility for developing the legislative and policy framework through which all health services are delivered, monitored, and measured in Ireland. The Department of Health is responsible for funding and overseeing the delivery of a wide range of health, mental health and disability services for adults and children through the Health Services Executive (HSE).(26) The Department of Education is responsible for education and training in Ireland. Its mission is to facilitate children and young people, through learning, to achieve their full potential and contribute to Ireland's social, economic and cultural development.(27) The special education section of the Department of Education is responsible for the development of educational policy for children with special educational needs and the development of comprehensive, efficient and effective education services for these children.(28)

At the time of this review, the HSE delivers services for children with disabilities through 91 Children's Disability Network Teams (CDNTs) across the country, which are located within nine Community Health Organisations (CHOs).* CDNTs sit within the Social Care Division of the HSE, with a designated National Director for Social Care. A CDNT is a team of health and social care professionals, supported by administration staff, who provide services for children with complex needs in a specific geographical area. Teams are comprised of occupational therapists, psychologists, physiotherapists, social workers, and speech and language therapists. Some teams may also have access to dietitians, family support workers, nurses, behaviour support workers or social care workers.(29)

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[*] The HSE is currently in the process of reorganising service delivery into six new regional health areas

In 2023, it was announced that the HSE would establish six regional assessment hubs in order to streamline the assessment of need process for children and young people with disabilities.(15)

The Health Information and Quality Authority (HIQA) is an independent authority established to drive high-quality and safe care for people using health and social care services in Ireland. HIQA has a remit to set standards for Ireland's health and social care services, including children's services and to monitor services against these standards. Under the Disability Act 2005, HIQA is the authorised body for setting standards for assessment of need. More detail on these standards can be found in Section 2.4.1. Under Section 5(5) of the Education for Persons with Special Educational Needs (EPSEN) Act, 2004, assessments must be carried out in a way that conforms to standards determined by HIQA.(4) However, this section has not been commenced. Due to this, no obligations currently arise for HIQA in terms of setting standards for special educational need.

The National Council for Special Education (NCSE) was set up to improve the delivery of education services to persons with special educational needs arising from disabilities, with particular emphasis on children.(30) Section 4 of the EPSEN Act 2004 provides for an assessment of special educational needs by the health board (now the HSE) or the National Council for Special Education (NCSE).(4) However, this section of the Act has not yet commenced. Following a High Court ruling in 2021, the NCSE has the responsibility to nominate an appropriate person to carry out an assessment of education needs on behalf of the HSE.(31) In 2024, the Department of Education announced that teachers have the appropriate expertise to assess a child's educational needs, as part of the overall assessment of need process. The Department of Education and the NCSE have guidance in place to support schools who are undertaking the educational component of assessment of need. However, the overall responsibility for the assessment of need process for children rests with the HSE, and teachers' assessments of a child's educational needs form only one part of the process.(32)

2.2.2 Scope

Under the Disability Act, an assessment of need application can be made for a child or young person who has, or may have a disability, born on or after 1 June 2002.(3) The legislation sets out that people with disabilities and or special educational needs are entitled to apply for an assessment of need, without regard to the cost or capacity to provide any of the service they need.

By law, the child or young person must have 'substantial restriction' to be entitled to services following an assessment of need. A substantial restriction means that the child or young person has a significant difficulty with communication, learning or mobility or significantly disordered cognitive processes. The child or young person must also have a restriction that is permanent (or likely to be permanent) and need for services to be provided continually. If the applicant is a child, there must be a need for services early in life to help their disability.(33)

2.2.3 Assessment of need process

The assessment of need process is outlined in the standard operating procedure published by the HSE in July 2023, together with interim guidance on assessment.(23) This section will provide detail on the assessment of need process under the following headings:

- Making an application
- Stage 1: initial contact
- Arranging assessments
- Stage 2: Clinical assessment stage
- Assessment of need report and service statement
- Review.

Making an application

An application can be made by a parent, legal guardian or personal advocate. A person aged over 16 can apply for their own assessment of need.(33) An assessment of need application form must be completed and returned to the local HSE assessment officer.(34) A HSE assessment officer is an officer appointed by the HSE to coordinate and arrange assessments of need as required under Part 2 of the Disability Act 2005; this is a non-clinical role. Local HSE assessment officers can provide additional information and assistance to applicants when completing the form.(33)

If the applicant is eligible under the terms of the Disability Act, the assessment officer refers the child for an assessment of need.(33) If at any time during the assessment of need process the assessment officer is of the opinion that intervention is required as a matter of urgency, they should ensure that an immediate referral is arranged to the relevant service provider.(23)

Stage 1: Initial contact

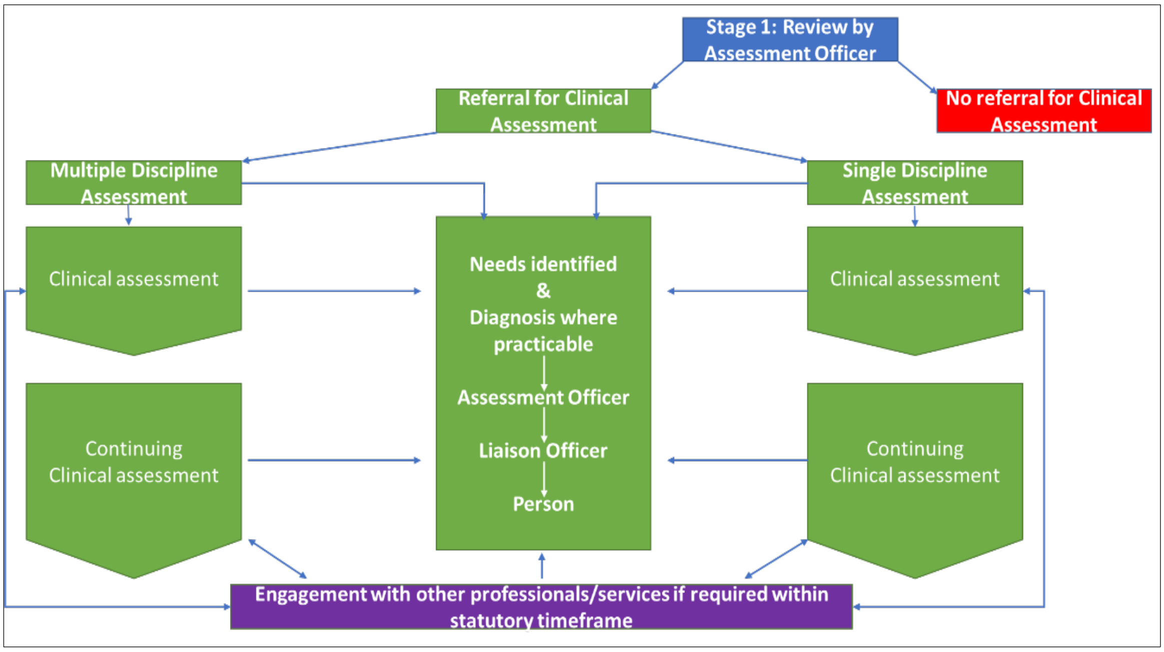
In line with the HSE SOP, applicants, parents or guardians should be contacted by the assessment officer in order to clarify why they think an assessment is required, gather further relevant information and explore their expectations of the assessment of need process.(23) Based on information provided in the application form and the initial contact with parents or guardians, the assessment officer will, at the earliest opportunity, contact relevant professionals to request copies of existing, relevant reports. A referral to the National Council for Special Education (NCSE) should be facilitated by the assessment officer for all children as early as possible in Stage 1 of the assessment of need process, to enable them to have an assessment of special educational needs.

Arranging assessments

It is the assessment officer's role to arrange for assessments to be undertaken. If the assessment officer is unsure of the appropriate pathway for the assessment, they will bring the referral to the Integrated Children's Services Forum[†] for discussion.(23) Usually, one to three clinicians are involved in an assessment of need, depending on the presentation and the relevance of different skill sets. One clinician representing a single discipline may be sufficient to assess some individuals. Previously, assessments of need have often involved an occupational therapist, a speech and language therapist and a psychologist. However, physiotherapists, paediatricians, psychiatrists, dietitians, nurses, social workers and other specialists may also be involved as required.(23) The assessment of need process is outlined in Figure 1.

[†] The Integrated Children's Services Forum is a meeting of relevant services and disciplines across the healthcare divisions such as primary care, social care and mental health and across relevant hospital services and other departments such as Tusla and education. It provides a mechanism for deciding where the child or young person's needs will be best met at any particular time, where it is unclear as to the pathway for a child or young person to receive services.

Figure 1. Assessment of need decision chart



Source: Health Service Executive. *Assessment of Need Standard Operating Procedure*. 2023. (23)

Stage 2: Clinical assessment phase

In the clinical assessment phase, it is the role of the clinicians to review the Stage 1 information and any related case file information. They should interview the person and relevant others; consider the developmental history, and observe the person. It is a matter for the clinical assessor, in the exercise of his or her clinical discretion, to decide if the use of any standardised assessment instruments is required and whether a physical assessment is needed. In some instances, an individual clinician or assessment team may decide to engage with other professionals or services that provide additional clinical skills that are necessary to identify a person's needs.

The HSE SOP provides a list of generic and specific assessment instruments which may be used, as appropriate. While it is not always necessary to provide a diagnosis, the judgment in the case of CTM & JA vs HSE 11 March 2022 found that, to the extent practicable at the time, the nature and extent of a disability should be fully assessed during Stage 2 of the assessment of need process.(35)

Assessment of need report and service statement

Following the receipt of relevant reports from the assessing clinician(s), the assessment officer produces the assessment of need report. The assessment of need report provides information on the needs of a child and it lists the services a child needs. If the child is deemed to have a disability, the assessment of need report will be given to a liaison officer. The liaison officer will use the report to draw up a service statement. A service statement lists the services the HSE proposes to provide to meet the child's needs. Importantly, when preparing the statement, the liaison officer must consider the cost and availability of services and the timescale for delivery of services.(33) After the service statement is complete, the liaison officer arranges the delivery of services with the different service providers. If needs other than health (for example, housing or transport) are identified, the assessment officer can refer the matter to the relevant public body, such as the local housing authority or public transport service.(33)

Review

When an assessment of need report determines that the applicant has a disability, the report will be subject to one review. As set out in the Disability Act, the review date will be no later than 12 months from the date on which the assessment of need report is issued. However, it is acknowledged that an earlier review may be appropriate if there is a significant change in the applicant's health or education needs. A review does not necessarily require further clinical assessment.

2.2.4 Appeals process

If an applicant wants to make a complaint about assessment of need, they can contact the disability complaints officer by submitting a complaint form. The disability complaints officer can make recommendations based on the complaint. If the HSE does not act on the recommendations of the disability complaints officer, the applicant can make an appeal to the disability complaints officer or they can go to the Circuit Court to seek an enforcement order.(33) Under the Disability Act 2005, a person may make a complaint to the HSE on:

- the determination that he or she does not have a disability
- the assessment not being commenced within the statutory time frame or not being completed without undue delay
- the assessment not being conducted in a manner that conforms to the national standards.

The complaints officer can make recommendations based on the complaint. The applicant can appeal those recommendations to an appeals officer. The appeals officer's determination is final, and can only be appealed on a point of law to the High Court. In 2022, 892 complaints were received in relation to assessment of need, an increase of 76% on 2021. Of these, 9% were recorded as resolved within 30 working days. Complaints highlighted the challenges people experience in relation to obtaining an assessment of need.(36)

2.3 Relevant legislation

This section outlines legislation relevant to assessment of need for children and young people. The central piece of legislation for assessment of need is the Disability Act 2005.(3) The Education for Persons with Special Educational Needs (EPSEN) Act, 2004 introduced a statutory system for the educational assessment, however the relevant sections have not yet been commenced.(4) The Health Act 2007 outlines HIQA's role in relation to assessment of need.(1) The legislation covered in this section is as follows:

- The Disability Act 2005
- The Education for Persons with Special Educational Needs (EPSEN) Act 2004
- The Health Act 2007
- High Court rulings on the assessment of need process.

2.3.1 The Disability Act 2005

The Disability Act 2005 was developed to promote the participation of people with disabilities in society, through the provision of disability-specific services and by improving access to mainstream public services.(3) The Act places a range of obligations on statutory services. These obligations include undertaking an assessment of need for children and adults with a disability, to make buildings and services accessible to people with disabilities, and sets out the requirement for sectoral plans in key service areas[‡].(3,37)

According to the Act, the definition of a person with a disability entitled to disability-specific services are those with a 'substantial restriction' which is permanent or likely to be permanent, and necessitates ongoing care and support.(3) If the person is a child, the Act indicates the need for services to be provided early in life to lessen the effects of the disability. The Act establishes the process for the assessment of need of a person with a disability, and sets out that the result of this assessment is an assessment report. This report indicates:

- whether a person has a disability and its nature and extent
- the health and education needs arising from the disability
- the services considered appropriate to meet those needs; the timescale ideally required for their delivery
- when a review of the assessment should be undertaken.

[‡] The NDA reports that these plans are longer in use.

The Act sets out that where a person is found to have a need for disability-related services, a service statement is prepared. The statement sets out the health and education services that can be provided to the person in line with their assessed needs. However, there are limits to the provision of these services, as they are dependent on the person's eligibility for services, the practicability of providing the service and the financial resources available. The Act also provides for a complaint system where an individual believes that there has been a failure to provide the service.

HIQA has a remit under Section 10 of the Disability Act 2005. It provides that where an assessment of need is carried out under the Act, the HSE must ensure that the assessment is 'carried out in a manner which conforms to such standards as may be determined from time to time by a body standing prescribed by regulations made by the Minister'.(3) Subsequently, HIQA was designated the prescribed body under Regulation 16 of the Disability (Assessment of Needs, Service Statement and Redress), Regulation 2007 (S.I. 263/2007).(38)

2.3.2 The Education for Persons with Special Educational Needs (EPSEN) Act 2004

The EPSEN Act 2004 sets out to promote inclusive education for children with special educational needs (SEN).(4) The Act established a statutory framework for the assessment of SEN and the development of individual education plans for children with such needs. The Act outlines the responsibilities of schools in this regard and provided for the establishment of the National Council for Special Education (NCSE).

However, only certain sections of the Act have been commenced. These are the sections that led to the establishment of the NCSE and these have been used to promote an inclusive approach to the education of children with SEN within the mainstream school system. Crucially, the parts of the Act that have not yet been commenced are those that relate to a child's right to assessment and their education plans. The 2020 report by the OCO highlighted that in the absence of a procedure under the EPSEN Act, students who require an assessment of their special educational needs are applying for an assessment of need under the 2005 Disability Act and that this places further pressure on the 2005 Act mechanism.(19)

A review of the EPSEN Act was undertaken by the Department of Education in 2022.(5) The purpose of the review was to provide assurance that the law that governs the provision of education for children with special educational needs is adequate. At the time of writing, the findings from this review have not yet been published.

2.3.3 The Health Act 2007

Since 1947, the Health Act has been continually reviewed and updated to provide a legislative framework for safer, better care for all those using health and social care services.(1) The Act provides for the establishment of statutory bodies to deliver health and social care services, the setting of regulations to enforce the delivery of the Act, and the establishment of a system of external oversight and monitoring of health and social care services.

The Health Act 2004 established the HSE as the single body with statutory responsibility for the management and delivery of public health and social services in Ireland, taking over the running of the 11 health boards that had previously administered health services.(39) The Act sets out that the HSE 'is to use the resources available to it in the most beneficial, effective and efficient manner to improve, promote and protect the health and welfare of the public.'(40) The overall aim of this centralised administration is to promote consistency, reduce costs and increase efficiency.

The Health Act 2007 makes a provision for the reform of the regulation of health and social care services in Ireland, providing for the establishment of HIQA. It also established a registration and inspection system for a number of residential services for children, including children in need of care and protection, as provided by special care units and children with a disability receiving care and support in residential centres. Under this Act, regulations to underpin this system are set out in the Health (Care and Welfare of Children in Special Care Units) Regulations 2017 and in the Care and Support of Residents in Designated Centres for Persons (Children and Adults) with Disabilities.(41,42) In addition to this, the Health Act 2007 also sets out HIQA's role in setting standards in relation to services provided by the HSE and Tusla.(1)

2.3.4 High Court rulings on the assessment of need process

In recent years there have been a number of applications for judicial review related to assessment of need.(21) As a result of this, the assessment of need procedure in Ireland has frequently been interpreted by the High Court. For example, in 2022, a High Court judgment found that the 2020 Standard Operating Procedure for Assessment of Need developed by the HSE did not fulfil the requirements of the Disability Act 2005 and the HSE then ceased the use of this SOP.(35) This ruling also stated that, to the extent practicable at the time, the nature and extent of a disability should be fully assessed during the assessment of need process. In April 2024, a high court judgment found that teachers have the appropriate expertise to be nominated by the National Council for Special Education (NCSE) to assess a child's educational needs, thus changing the process for assessment of special education needs.(32,43) Further details of how these rulings have affected the assessment of need process detailed throughout Section 2.

2.4 Standards, policies, frameworks and strategies

The key standards in this area are the *Standards for the Assessment of Need* (2007). A number of policies, strategies and frameworks are in place at Government and HSE level. This section will provide detail on:

- standards
- policies
- frameworks and strategies.

2.4.1 Standards

The key national standards for assessment of need in Ireland are the *Standards for the Assessment of Need*.(6) Under the Disability Act 2005, HIQA is the authorised body in setting standards for assessment of need. In 2007, in advance of the establishment of HIQA, a cross-sectoral group established by the then Department of Health and Children and the Department of Education and Science developed the *Standards for the Assessment of Need*. These standards were adopted by the Board of the interim Health Information and Quality Authority (iHIQA) and subsequently, by the HIQA Board.(6) As they were developed in 2007, these standards include out-of-date references and are not aligned with HIQA's current approach to development of national standards.(8,10) To date, services undertaking assessment of need have not been monitored against these standards.

The *Standards for the Assessment of Need* document outlines that the standards are the desired and achievable levels of performance against which actual performance can be measured. Each standard has a number of criteria by which the meeting of each standard can be judged. The standards were intended to ensure that each assessment of need is conducted in a consistent manner in order to accurately and efficiently identify the needs of the person being assessed. The standards document is divided into six standards:

- person-centred approach
- information
- access to the assessment of need
- involving appropriate education and health staff
- coordination of the assessment of need

- monitoring and review.(6)

In terms of wider disability services, HIQA has developed *National Standards for Residential Services for Children and Adults with Disabilities* (2013).(44) These standards set out what a good quality, safe residential service for people with disabilities should be. HIQA, in partnership with the Mental Health Commission has also developed *Draft Overarching National Standards for the Care and Support of Children using Health and Social Care Services* (2021), which at the time of this review are awaiting ministerial approval.(45) These standards aim to promote high quality and safe care and support for children using health and social care services and progressive quality improvements in that care and support. The standards outline what a child should expect from a service when their needs are being assessed. In relation to disability day services, the HSE has commenced the implementation of the *Interim Standards for New Directions*.(46) More information on these how these standards are implemented and monitored can be found in Section 2.5.

2.4.2 Policies

There are two important Health Service Executive (HSE) policies and procedures that inform the delivery of assessment of need and access to services for children with disabilities. This section will provide information on the:

- HSE Assessment of Need Standard Operating Procedure (2023)
- HSE National Policy on Access to Services for Children and Young People with Disability and Developmental Delay (2019).

HSE Assessment of Need Standard Operating Procedure (2023)

In 2009, the HSE developed a range of guidance and processes to support the implementation of the process for the assessment of need. This included guidance for assessment of need under the Disability Act 2005, Guidance for Assessors and Assessment Officers and Process and Practice Guidelines, which were developed by an assessment of need process HSE working group.(17) In 2011, the National Disability Authority (NDA) published a report highlighting significant differences in the systems, the time and the resources across the teams tasked with assessing children with disabilities.(17) In 2016, an internal HSE review confirmed the approach to assessment of need was not consistent across the country.(18)

In response to these issues, the HSE introduced a Standard Operating Procedure for Assessment of Need (SOP) in 2020. The SOP included a preliminary team assessment, which was a less comprehensive assessment than what had been in place previously. It aimed to have a shorter assessment time and allowed for assessment to continue as part of routine clinical practice. The SOP outlined that in cases where the Preliminary Team Assessment (PTA) was not sufficient, then a more detailed assessment would follow. Concerns were raised at the time about the PTA approach, including in the report *Unmet Needs: A report by the Ombudsman for Children's Office on the challenges faced by children in Ireland who require an assessment of their needs* (2020).(19) This report raised serious concerns about the new SOP and violations of the rights of children with disabilities. Many stakeholders were concerned that the PTA would not provide an effective assessment of a child's needs.(21) In 2022, a High Court judgment found that the 2020 Standard Operating Procedure for Assessment of Need did not fulfil the requirements of the Disability Act 2005 and the HSE ceased the use of this SOP.(35)

In July 2023, the HSE published an updated Standard Operating Procedure for assessment of need (SOP).(23) The purpose of this updated SOP is to ensure that there is a consistent approach to managing requests for a statutory assessment of need and processing the resulting referrals. The procedure applies to all assessment officers and clinicians involved in the assessment of need process.

An assessment officer is an officer appointed by the HSE to coordinate and arrange assessments of need as required under Part 2 of the Disability Act (2005).

More detail on the assessment of need process is set out in Section 2.2.3.

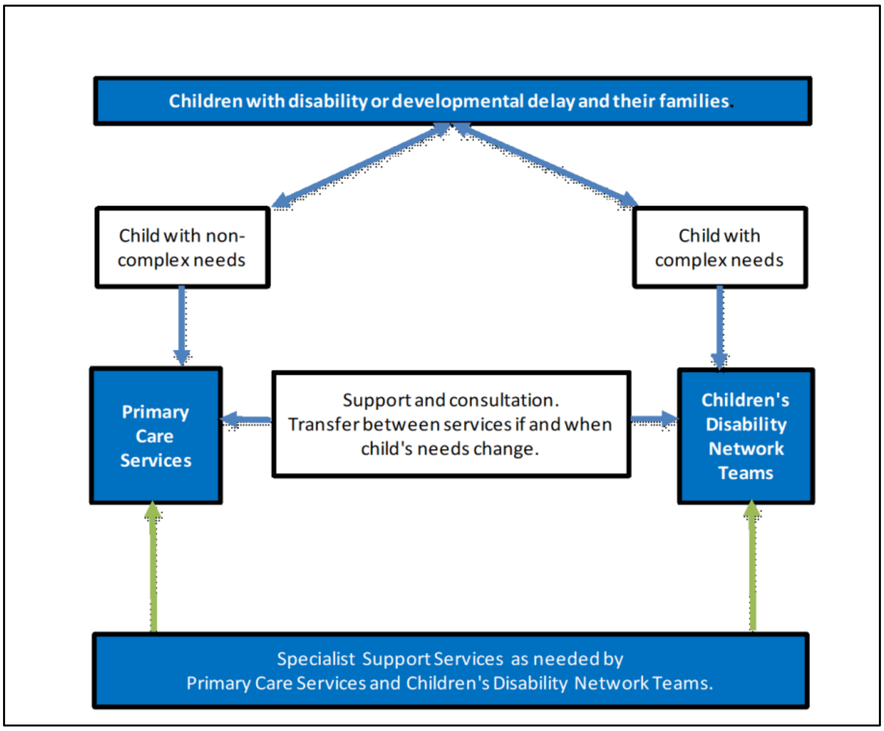
Templates and forms are provided in appendices to the HSE SOP, which include:

- Standard letters
- Assessment of need application form
- Incomplete assessment agreements
- NCSE referral form
- Guidance for assessors
- Summary report form
- Interparty agreement for private assessments
- Assessment report – no disability
- Assessment report disability
- Review report.

HSE National Policy on Access to Services for Children and Young People with Disability and Developmental Delay (2019)

The *HSE National Policy on Access to Services for Children and Young People with Disability and Developmental Delay* was developed in the context of restructuring delivery of services as part of the 'Progressing Disability Services for Children & Young People' Programme.(47) Access to services is a critical part of the programme. The policy aims to give clarity on access for children and young people and their families to both children's disability services and primary care services. An assessment of need under the Disability Act is not necessary in order to access health or social care services; an overview of how children and their families access services can be found in Figure 2, below.

Figure 2. Access to Services for Children and Young People



Source: Health Service Executive. *National Policy on Access to Services for Children & Young People with Disability & Developmental Delay*. 2019.(47)

The principles underpinning the policy are as follows:

- Services exist to support children, young people and their families.
- Access to services is equitable.
- Access to services is needs led rather than diagnosis led.
- Children are seen at the level of service nearest their home which best addresses their needs.

- No child is left without timely access to an appropriate service to meet their needs.
- Parents know their child better than anyone else and should be treated by professionals as equal partners, given the expertise they have in the care of their child.
- A family-centred approach is a continuing process that begins at the moment of initial contact with families.
- A child's need for services does not exist in isolation from their other needs and from the needs of their family.(47)

2.4.3 Frameworks and strategies

There are a number of important frameworks and strategies that have been developed at a national level in recent years to support children and young people with disabilities. This section will provide information on:

- Progressing Disability Services for Children and Young People
- Roadmap for Service Improvement 2023 – 2026: Disability Services for Children and Young People (2023)
- Action Plan for Disability Services 2024 – 2026 (2023)
- Young Ireland: the National Policy Framework for Children and Young People (0-24) 2023-2028 (2023).

Progressing Disability Services for Children and Young People

The HSE's national programme Progressing Disability Services for Children & Young People was established in 2010, with the aim of ensuring that services are provided equitably and consistently for all children. Children do not need to have an assessment of need, as set out under the Disability Act, to access these services. When the programme is completed, the aim is that there will be Children's Disability Network Teams (CDNTs) across the country for all children with complex needs to access.(24) The programme outlines a vision for children's disability services where:

- there is easy access to the services children need
- there is fairness in providing services
- families, health services and schools are working together to support children in developing their potential.

As part of this programme, the HSE developed a *Roadmap for Service Improvement 2023 – 2026: Disability Services for Children and Young People*, details of which are set out below.

Roadmap for Service Improvement 2023 – 2026: Disability Services for Children and Young People (2023)

The *HSE Roadmap for Service Improvement 2023 – 2026: Disability Services for Children and Young People* aims to achieve a quality, accessible, equitable and timely service for all children with complex needs as a result of a disability, and their families.(15) The roadmap identifies delivery of assessment of need as a significant challenge for CDNTs.

As of 2023, the HSE and its partner agencies were providing CDNT services for over 45,740 children.(15) There were 1,395 health and social care professionals and administrative staff in 91 teams across the country working with children with disabilities and their families. The roadmap notes that CDNTs have a national average vacancy rate of 34%, with some teams experiencing over 60% vacancy rates.(15) The current annual assessment of need rate of over 7,600 requires 285 clinicians dedicated full time to complete in one year, which draws from the limited resources available for therapeutic supports for children and families.

In regard to assessment of need, implementation of the roadmap aims to:

- maximise the use of voluntary and private disability service providers for children on CDNT waiting lists, to ensure optimisation for delivery on assessments of need and where appropriate, interventions, based on individual provider’s capacity and capability
- improve HSE’s legislative compliance for assessment of need as defined in the Disability Act.

The HSE roadmap outlines the following list of actions to be taken in respect of assessment of need, with their target dates:

- the HSE will complete the set-up of six assessment hubs to streamline the assessment of need process, separating it, where required, from the work of CDNTs (Aug 2023)
- a tender process is in train to establish a framework for external service providers on provision of assessment of need to support CHOs in achieving their targets (Oct 2023)
- each CHO will provide a CHO-specific service improvement plan, including monthly targets on assessment of need and first appointment for their waitlisted children (Dec 2023)

- the HSE will consult with families, staff and other stakeholders, to inform a proposal for balancing competing demands of assessment of need and service provision for children while staff resources are limited (Dec 2023)
- the National Clinical Programme for People with Disabilities will set up a task group to address any outstanding clinical issues for assessment and intervention, post release of the Revised Assessment of Need Standard Operating Procedure (Dec 2023)
- an independent review of the CDNT service model by the NDA will include a review of competencies and skill mix required and staffing to child population ratios across teams, to optimally support children and families (Q4 2024).

To ensure implementation of the roadmap, an interdepartmental oversight group has been established, with members from the HSE, DCEDIY and Department of Education, chaired by the Minister for State with responsibility for Disability. A community operations integrated services group including primary care, Child and Adolescent Mental Health Services (CAMHS) and disability services is leading on implementation of the national access policy and a joint protocol for children with disabilities, to ensure all assessments of need are routed to the most appropriate service, such as primary care, CDNT or CAMHS. This group is be chaired by the Director of HSE Community Operations and reports to a service improvement programme board. Reports of progress on implementation of the roadmap targets are to be published quarterly on the HSE’s website. At the time of this review, no reports had yet been published. The HSE quarterly performance profile July-September 2023 contains no data on assessment of need due to industrial action.(48) The quarterly performance profile April-June 2023 details the number of assessment of need requests received and Disability Act compliance per CHO.(49) The highest level of compliance was in CHO 5, with 36.4% of assessments of need completed within the statutory timeframe. CHOs 7 and 9 had 0% compliance.

Action Plan for Disability Services 2024 – 2026 (2023)

The *Action Plan for Disability Service 2024-2026* is a plan, set out by the Department of Children, Equality, Disability, Integration and Youth (DCEDIY), for increasing capacity in and access to disability services.(50) The plan outlines actions for the period 2024-2026 under three key areas:

- providing better access to services
- maximising impact of service delivery
- improved planning and management through better information and systems.

The plan sets out a three-year programme designed to tackle the deficits highlighted in the *Disability Capacity Review to 2032 - A Review of Social Care Demand and Capacity Requirements to 2032*.(16,50) Further detail on this review is set out in Section 2.6.3. The focus of the action plan is on developing supports and services that are person-centred, give individuals choice and control, and support people with disabilities to live ordinary lives in ordinary places.

In relation to assessment of need, the plan outlines that the HSE will explore alternative solutions for the conduct of assessment of needs using a revised interim clinical guidance on assessment, including assessment teams and assessment hubs. These teams and hubs will aim to deliver assessments and preserve resources for therapy interventions. An action is also included for the HSE to roll out the Assessment of Need Tracking System for children and adults as part of the National Children's Disability Network Team Information Management System (CDNTMIS) in 2024.

Young Ireland: the National Policy Framework for Children and Young People (0-24) 2023-2028 (2023)

Young Ireland is the new policy framework for children and young people aged 0-24. It covers the period from 2023-2028, and envisages an Ireland in which all children and young people can fully access their rights.(51) It is focused on tackling the biggest challenges that affect children and young people in Ireland today, and setting up robust structures so children’s rights are foremost whenever decisions are made affecting the lives of children and young people. A new Children and Young People’s Indicator Set has been released to align to the targets set out in Young Ireland.(52)

The Young Ireland framework seeks to address, amongst other things, capacity deficits within the HSE’s community-based specialist disability services programmes.(51) Some of the priority areas of action in this regard are as follows:

- reduce waiting lists
- increase capacity to enhance service delivery
- tackle the demand for assessment of need in a timely manner
- support children in care
- education
- social inclusion
- pathways for school leavers

- inclusive participation structures.

The framework outlines that early intervention is critical to delivering good outcomes for children and young people, and in general the faster a response is delivered, the greater its impact.(51) Focusing on the prevention of problems from arising, and intervening early when they arise, is typically the most rational and effective use of resources. The framework highlights that there are particular difficulties with assessing the needs of children and young people, which must be addressed as a priority.

2.5 Monitoring of assessment of need

Section 10 of the Disability Act 2005 provides that where an assessment of need is carried out under the Act, the HSE must ensure that the assessment is carried out in a manner which conforms to standards that have been set by HIQA.(3) The HSE currently publishes data only on the timeliness of assessment of need, and numbers of assessments completed per CHO each quarter.(53) As noted, to date, services have not been monitored against the standards.(6)

In terms of wider disability services, HIQA has a remit in monitoring, inspecting and registration of residential centres for adults and children with disabilities. This is conducted under the Health Act 2007 (Registration of Designated Centres for Persons (Children and Adults) with Disabilities) Regulations 2013 and the Health Act 2007 (Care and Support of Residents in Designated Centres for Persons (Children and Adults) with Disabilities) Regulations 2013.(42,54) HIQA also uses the *National Standards for Residential Services for Children and Adults with Disabilities* to assess what a good quality, safe residential service for people with disabilities should be.(44)

In relation to disability day services, the HSE's National New Directions Implementation Group (NDIG) commenced the implementation of the Interim Standards for New Directions by focusing on self-evaluation and continuous quality improvement; this approach is branded EASI (Evaluation, Action and Service Improvement).(46) The purpose of the EASI approach is to explore and reflect with all stakeholders (people using the service, staff and local management) and to report on the effectiveness and quality of the supports being provided under New Directions.(55)

2.6 Findings from reviews

Due to ongoing issues with the delivery of assessment of need, there have been a number of reviews carried out by the Ombudsman for Children's Office (OCO), the Joint Committee on Children, Equality, Disability, Integration and Youth and the National Disability Authority (NDA). This section will include information on:

- Joint Committee on Children, Equality, Disability, Integration and Youth Report on Assessments of Need for Children (2023)
- Mind the Gap: Barriers to the realisation of the rights of children with disabilities in Ireland (2021)
- The Disability Capacity Review to 2032 - A Review of Social Care Demand and Capacity Requirements to 2032 (2021)
- Unmet Needs: A report by the Ombudsman for Children's Office on the challenges faced by children in Ireland who require an assessment of their need (2020)
- Report to the Minister of State with special responsibility for Disability Issues at the Department of Health as provided for under Section 13 of the Disability Act 2005 in respect of data collected in 2016
- Report on the Practice of Assessment of Need under Part 2 of the Disability Act 2005 (2011).

2.6.1 Joint Committee on Children, Equality, Disability, Integration and Youth Report on Assessments of Need for Children (2023)

As part of its work programme from 2020 to 2022, the Joint Committee on Children, Equality, Disability, Integration and Youth examined the report by the Ombudsman for Children's Office entitled *Unmet Needs: A report on the challenges faced by children in Ireland who require an assessment of their needs*.(21) As part of its examination of the issues detailed in that report, the committee invited a number of stakeholders and experts in the field to appear before it over the course of six Committee meetings. The Committee also invited written submissions from a selection of stakeholders. Many of the issues flagged and recommendations made by stakeholders, such as the need for more collaboration with therapists and parents, echo those that have been made by a number of organisations over a number of years.(17,19) According to the committee report, it became clear during their deliberations that the same problems have existed for over a decade and these problems have been consistently highlighted by those working in the sector and by parents.

The joint committee made a number of recommendations in the following areas:

- resources and capacity
- recruitment and retention
- systems and organisation

- the assessment
- standards, acts and conventions.

The report recommended a review of both the Disability Act and ESPEN Act in tandem, while ensuring there is no dilution of rights on foot of the reform of these acts. The report also called for the ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) Optional Protocol without delay. This protocol creates additional mechanisms for monitoring and evaluation under the UNCRPD. Additionally, the report recommended that the United Nations Convention on the Rights of the Child (UNCRC) should be incorporated into domestic law as a matter of priority. The report also recommended that HIQA be resourced to provide appropriate and up-to-date standards for assessment of need and that these standards should be developed as a priority.(21)

The report recommended that input from disabled people, families, carers and therapists should be central to the design of any new procedures for assessment of need and central to the work of the National Clinical Programme for People with Disabilities.

The report included recommendations on progressing the audit of the HSE's Progressing Disability Services and ensuring independent experts are involved in the audit. The report set out that the audit should assess how the National Clinical Programme for People with Disabilities is working, including analysing how many people with lived experience of having a disability are involved, whether that amount is enough, and whether they are being enabled to provide meaningful input into the relevant fora and policies. In relation to recruitment and retention of staff in disability services, the report recommended that a more efficient system be put in place for recruitment, to include the employment of a sufficient number of therapists to manage the increasing number of applications for assessment of need.

In May 2024, the Joint Committee on Children, Equality, Disability, Integration and Youth published the *Report on CAMHS and Dual Diagnosis*.(56) This report notes that the issues highlighted in the 2023 report on assessment of need have continued to worsen and makes a number of recommendations to improve staffing levels in services.(56,57)

2.6.2 Mind the Gap: Barriers to the realisation of the rights of children with disabilities in Ireland (2021)

This research was commissioned by the Ombudsman for Children's Office (OCO) and undertaken by researchers at the School of Law and the Institute for Lifecourse and Society at NUI Galway.(20) The research found that children with disabilities are often invisible, as they are overlooked in many child and disability focused laws, policies and programmes. Children with disabilities are not heard, as they are not actively or effectively involved in consultations on laws, policies and programmes affecting them. The research also noted that children with disabilities are not counted, as they are relatively invisible in official data.

The research raised concerns about the ongoing violation of the rights of children with disabilities and recommends several actions to remedy this, taking a child-centred and rights-based approach. The report aimed to draw attention to the need for more targeted legislative, administrative and other measures directed at children with disabilities to reflect the realities of their lives and ensure that their human rights are respected.(20)

2.6.3 The Disability Capacity Review to 2032 - A Review of Social Care Demand and Capacity Requirements to 2032 (2021)

The Department of Health conducted the *Disability Capacity Review to 2032 - A Review of Social Care Demand and Capacity Requirements to 2032*.(16) The review examined the implications of anticipated changes in the size and structure of the population with disabilities, and estimated the scale of unmet need to be addressed. It also considered the combined impact of a change in the baseline level of service to tackle unmet need, and likely demographic change. The review identified significant levels of unmet need for disability services, and found that changes in the size and age profile of the population requiring disability services will add to unmet need over the coming decade.

The review outlined that children with disabilities are experiencing difficulties in accessing primary care therapies. Some key findings were also identified in relation to multidisciplinary therapy services:

- Multidisciplinary therapies play a vital role in maximising the potential of those born with a disability and in rebuilding capacity of those who have acquired a disability.
- There are significant shortfalls in access to specialist disability therapy services for both adults and children, and their access to mainstream therapies via primary care is sporadic.
- Demographic demand for children's therapy services, at current use rates, will be broadly stable up to 2027, as fewer young children will be largely counterbalanced by larger numbers of teenagers. By 2032, however, the total number of children will fall, lowering demand for children's therapy services by about 10%.
- The number of adults with a disability will rise steadily. Taking adults and children together, total numbers of people with disabilities will rise.

- The combined impact of addressing unmet need and of demographic change will raise overall demand for therapy services by about two thirds by 2032.(16)

Based on the findings of this review, the *Action Plan for Disability Services 2024 – 2026* (2023) outlines key actions to be taken to tackle the deficits highlighted.(50) More information on this can be found in Section 2.4.3.

2.6.4 Unmet Needs: A report by the Ombudsman for Children's Office on the challenges faced by children in Ireland who require an assessment of their needs (2020)

A key report in the area of assessment of need is the Ombudsman for Children 2020 report, *Unmet Needs: A report on the challenges faced by children in Ireland who require an assessment of their needs*.(19) The report raised concerns about ongoing violations of the rights of children with disabilities and recommended several actions to remedy this, taking a child-centred and rights-based approach.

Among the issues highlighted are the significant and lengthy delays being faced by children and their families in the completion of an assessment of need, despite a legal requirement to begin the assessment of need within three months of receiving an application. The report found that the demand for applications for assessment of need had quadrupled between 2007 and 2018, with just 8.8% of assessments completed on time in 2018.

The report highlighted issues with the Disability Act 2005, including that the legislation is based on a diagnoses-led model, rather than a needs-led model. Furthermore, the report found that the Disability Act contains an adult definition of disability. With its emphasis on productivity and participation, this definition fails to account for the child and their needs. The report set out that the focus should be on the early identification of needs rather than the early diagnosis of disability.

The OCO made a recommendation that the Disability Act should be reviewed, with consideration given to adopting a human-rights based approach to disability. It recommended amending the definition of disability within the Act to a definition which is rights-based, child-centred and inclusive. It also recommended amendment of the Disability Act to ensure a best interest, holistic, multidisciplinary, needs-based approach to assessment of need. In the report, the OCO noted that the EPSEN Act is more akin to a needs-led model and is of the view that legislative underpinning for the special educational needs of children is vital to ensuring that children's needs are identified and met in a timely and appropriate manner. To achieve this, the report stated that the commencement of sections 3 to 13 of the EPSEN Act must be considered together with a review of the Disability Act.(19)

The OCO also recommended that the State must undertake a review of the access criteria for all services for which a diagnosis is still generally required, and ensure a clear pathway to services for all children according to need. This would include a needs-based framework for access to services provided by voluntary bodies, and education services, such as special classes, the school transport scheme, home tuition, special needs assistants, and the assisted technology scheme.

Additionally, the OCO called for the development of a new set of national standards for the assessment of need for children with disabilities, in order to create an overarching framework of high level principles through which actual care can be consistently measured against optimal care. The OCO further recommended that the State ensure that a functional and accessible complaints mechanism remains in place for children to seek and obtain effective and timely remedies.

The OCO recommended that the HSE collect and create a central database of assessment of need data, which is accessible to all therapists, clinicians and administrators involved in the assessment of need process. The database should allow access to information on a real-time basis in relation to the waiting times for appointments and the availability of services detailed in the service statement. This would allow disability teams to plan and respond appropriately.

In relation to communicating and engaging with children and families, the OCO recommended that the HSE create information materials for both parents and children to guide them through the assessment of need process. These information materials should be made available upon acknowledgement of receipt of a child's application, and should be child-friendly when directed at children and young people. The OCO also recommended that the HSE commit to meaningful engagement with children with disabilities, their parents, professional bodies and service users, in order to ensure that SOPs are aligned with a rights-based and needs-based approach and are based on updated standards and the best available evidence.(19)

2.6.5 Report to the Minister of State with special responsibility for Disability Issues at the Department of Health as provided for under Section 13 of the Disability Act 2005 in respect of data collected in 2016

In 2016, the HSE conducted an internal review of the practice of implementation of Part 2 of the Disability Act.(18) The review examined activity data from the four HSE quarterly 2016 assessment of need management reports. The review found a number of shortcomings in the assessment of need process. It found that there was a difference between the identified needs of children, as outlined in their assessment reports, and the services that were being provided to them. This was due to a range of factors including staffing levels, demand levels and availability of specialist support.

The HSE recognised that it faced significant challenges in respect of meeting the statutory timeframes which apply to the assessment of need process. A working group was established to examine the issues involved in the continued poor performance against assessment of need targets, with a view to identifying best practice and issuing recommendations and updated guidelines to improve performance.

The review highlighted that early intervention is a key component to supporting children and that the fact that a child is awaiting an assessment of need should not mean that they cannot access services while they wait. The report set out that direct referral to services should be considered for children, as required.(18)

The review noted that the approach to assessment of need was not consistent across the country.(18) It was apparent that practice varied widely across the nine Community Health Organisations (CHOs) as well as within CHO areas. While a large number of 'guidance notes' regarding assessment of need processes had been issued since 2007, there had been no nationally standardised or agreed definition of an assessment of need. This led to an inconsistent approach to assessment, as well as inequity in terms of time afforded to 'assessment' versus 'support or treatment' interventions with children and their families. To help address this situation, the HSE implemented a Standard Operating Procedure for the Assessment of Need (2020) to ensure that the approach to assessment of need was consistent across all areas.(58)

2.6.6 Report on the Practice of Assessment of Need under Part 2 of the Disability Act 2005 (2011)

In 2011, the National Disability Authority (NDA) published a report on the practice of assessment of needs under the Disability Act.(17) It highlighted inconsistent service provision and reported that although HSE guidelines were in place at the time, they were having little impact. The NDA reported that local management by the HSE was weak regarding oversight and coordination of the statutory assessment of need process in some Local Health Office areas. As a result, there appeared to be very little feedback and or direction on how statutory assessments were being conducted by clinicians. The report also highlighted significant differences in the systems, amount of time and resources being used to assess children with disabilities across teams and an over-reliance on diagnosis as opposed to needs. The NDA highlighted that a diagnosis should not be a prerequisite or determinant for the allocation of resources for a child or young person.(17)

The report noted that there were increasing referrals from the education sector, as the relevant sections of the EPSEN Act had not been commenced.(17) The deferral of the enactment of assessment under the EPSEN Act resulted in some children with educational support needs being channelled through the statutory assessment of need process, increasing waiting lists.

A number of key areas for future consideration were also identified in the report, these included the need to:

- develop a mechanism, such as a legal instrument, to bring greater clarity as to what is legally required of assessors
- integrate early intervention and children's disability services
- provide assessors with feedback and ongoing mentoring on the requirements of statutory assessment of need process
- facilitate engagement between Department of Health and Department of Education and Skills on specific issues, and in particular on the issue of the incompatibility of the statutory assessment of need process and the resource allocation rules operated by the Department of Education and Skills.(17)

2.7 Summary

There have been a number of national reports in relation to assessment of need in Ireland. National reports on assessment of need by the Joint Committee on Children, Equality, Disability, Integration and Youth, the Ombudsman for Children Office (OCO) and the National Disability Authority (NDA) have found inadequacies in a number of areas, including extensive waiting times for an assessment, a lack of early intervention to address the needs of children and too great a focus on diagnosis of disability in order to gain access to services, rather a holistic focus on their strengths and needs.(17,19,21) These reviews have raised serious concerns about ongoing violations of the rights of children with disabilities and the need to take a child-centred and rights-based approach to assessment of need.(19,20)

National reports on assessment of need have called for a review of the legislation relating to assessment of need, to ensure a best-interest, holistic, multidisciplinary, needs-based approach to assessment. Reports by the Joint Committee on Children, Equality, Disability, Integration and Youth, the OCO and the NDA have called for an update to the Disability Act and the Education for Persons with Special Education Needs (EPSEN) Act to enable a best interest, holistic, multi-disciplinary, needs-based approach to assessment of need. (17,19,21) The Disability Act 2005 gives the right to an assessment of need, but does not give people the right to services following an assessment. Additionally, the current interpretation of the Act has resulted in a diagnoses-led model, rather than a needs-led model.(19) The Disability Act contains an adult definition of disability.(19) With its emphasis on productivity and participation, reviews have found that this definition fails to account for the child and their needs. Subsequent reviews have highlighted the need to amend the definition of a disability to one that incorporates a rights-based, child centred and inclusive approach.(19,21) As the relevant sections of the EPSEN Act have not been commenced, clarity is required on how assessment of education needs is conducted, leading to many families using the assessment of need process to access education services, increasing the already lengthy waiting lists.(17)

Further changes to the assessment of need process have arisen from the intervention of the courts. In 2020, the HSE Standard Operating Procedure on Assessment of Need included a Preliminary Team Assessment (PTA). This preliminary assessment was a less comprehensive initial assessment to identify the child's needs, followed by a subsequent full assessment, where required. A High Court ruling found that the 2020 Standard Operating Procedure on Assessment of Need did not meet the requirements of an assessment of need, as set out under the Disability Act and the HSE ceased its use.(35) This ruling also stated that, to the extent practicable at the time, the nature and extent of a disability should be fully assessed during the assessment of need process and this ruling has resulted in a mostly diagnostic approach to assessment of need. A number of High Court judgments have also led to changes in how educational assessments are carried out as part of the assessment of need process.(43) In April 2024, the Department of Education announced that teachers have the appropriate expertise to be nominated by the NCSE to assess a child's educational needs as part of the assessment of need.(32)

While *Standards for the Assessment of Need* are in place, they are limited to the assessment process only, whereas generally, national standards developed by HIQA and similar organisations internationally, are wider and are focused at a systems level. Neither the standards nor the assessment of need process infer an entitlement to the services identified in the assessment of need process, and therefore the impact on outcomes for people may be limited.

At the time of writing (June 2024), the NDA was conducting an independent review of the Children's Disability Network Team (CDNT) service model. The outcomes of this review will provide important insights in relation to assessment of need in Ireland.(22)

3. Approaches to assessment of need internationally

Internationally, the approaches to assessment of need for children and adults with disabilities varies considerably. Ireland is unique in having a set of national standards specific to the assessment of need process, the requirement for which is set out in law.(6) There are important lessons to be learned for Ireland from the approaches taken in other countries to assessment of need, particularly in relation to the:

- supporting legislation
- holistic approach to assessment of need
- whole system inter-agency approach that includes assessment of need
- assessment of special education needs
- use of standards and guidance
- how assessment of need is regulated, monitored and inspected
- challenges faced in relation to assessment of need.

The review of international approaches set out in this document provides an overview of how 10 jurisdictions deliver assessment of need services to people with disabilities. The jurisdictions included in the review are:

- England
- Northern Ireland
- Scotland
- Wales
- New Zealand
- Australia
- Iceland
- Romania
- Singapore
- Hong Kong.

These 10 jurisdictions were selected following an initial scoping review of 34 jurisdictions, listed in appendix 1. The reasons for inclusion for in depth review were;

- there was recent reform related to assessment of need
- these jurisdictions were experiencing similar issues to Ireland
- these jurisdictions provided examples of best practice
- and there were learnings to be gained from their experience of delivering assessment of need in practice.

A further desktop review of these 10 jurisdictions involved web-based searches of relevant literature and websites which identified a number of key organisations and experts to engage with. Online meetings were held with international subject matter experts to understand how assessment of need works in practice within these jurisdictions. Meetings were held with experts in England, Northern Ireland, Scotland, Wales, New Zealand, Australia, Iceland and Romania between January and April 2024. See appendix 2 for the list of organisations contacted within these jurisdictions. Contact was made with organisations in Singapore and Hong Kong by email to gather additional information.

The subject matter experts contacted were primarily working in key organisations responsible for delivering and or regulating assessment of need for people with disabilities. They provided information on how assessment of need is implemented within their jurisdiction and the current barriers and challenges they face in conducting assessment of need and coordinating and delivering services following assessment. They also provided relevant reference material and supporting documents following the meetings. Lessons from delivering assessment of need and follow-on services for people with disabilities were also discussed. For each of the international jurisdictions, the review looks at seven areas:

1. Overview of assessment of need
2. The model of service
3. Relevant legislation
4. Standards, guidance, frameworks, strategies and policies
5. Regulation, monitoring and inspection of assessment of need
6. Findings from reviews
7. Summary and lessons for Ireland.

Population-level statistics are provided for the general population and for people with disabilities within each jurisdiction. At the time of writing, it was not possible to obtain statistics in each jurisdiction for the number of children or adults with disabilities, or the number of people awaiting an assessment of need. Therefore, we have presented the population of people with disabilities as a percentage of the overall population.

3.1 England

This section describes the organisation and delivery of assessment of need services in England. The section is set out under the following headings:

- overview of assessment of need
- the model of service
- relevant legislation
- standards, guidance, frameworks, strategies and policies
- regulation, monitoring and inspection of assessment of need
- findings from reviews
- key findings.

3.1.1 Overview of assessment of need

In England, people with disabilities have a statutory entitlement to an assessment of need, the provision of services and continuity of care and support. Legislation in England sets out the responsibilities and functions of the local authorities to conduct assessments of need, to promote interagency cooperation and to ensure integrated working to improve the welfare of children. Legislation also promotes the physical, mental health and emotional wellbeing of children and young people with special educational needs or disabilities and sets out the requirement to involve children and young people in their assessments. In 2022, the population of England was estimated to be 67.6 million people and people with a disability accounted for 24% of the population.(59,60)

Local authorities are responsible for carrying out assessments of need, and for developing their own protocols for the assessment process, in line with the statutory guidance *Working Together to Safeguard Children* (2023).(61) In England, assessment of need is known as 'needs assessment' and is provided for anyone who appears to have needs for care and support. Children with disabilities may request or are referred for an Education, Health and Care (EHC) needs assessment, which may result in the creation of an EHC Plan. In more complex cases, or where there is also a child protection concern, a child may be referred for an Early Help assessment or a statutory 'children in need' assessment. There are local protocols for assessment requests and referrals, for example, from a health or education professional. It is not necessary for an assessment to be fully completed before beginning to deliver services, where needed.

There are no specific standards for the assessment of need. The primary guidance for Early Help and 'child in need' assessments is the statutory guidance *Working Together to Safeguard Children: A guide to multi-agency working to help, protect and promote the welfare of children* (2023), while Special Educational Needs and Disabilities (SEND) assessments must adhere to the statutory guidance *Special educational needs and disability code of practice: Code of Practice 0 to 25 Years* (2015).(61,62) Joint monitoring and inspection of local authority children's services, including needs assessments, is undertaken by the Care Quality Commission (CQC) and the Office for Standards in Education, Children's Services and Skills (Ofsted). The *SEND Review* (2023) released statistics on child protection plans, referrals to children's social care services and assessments completed by children's social care services. In 2022, the *Independent Review of Children's Social Care* (2022) proposed a restructuring of children's social care and the introduction of one category of 'Family Help' to replace targeted Early Help and Child in Need work, which would be delivered by multi-disciplinary teams. Both reviews have informed the recent and upcoming reforms in provision for SEND and social care.(63,64) National standards are currently in development for the SEND system, and it is expected that these will be published by 2025.

3.1.2 The model of service

In England, responsibility for the delivery and organisation of assessment of need lies with local authorities. This section sets out the model of service under the following headings:

- structure and governance of assessment of need
- scope of assessment of need
- assessment of need process
- appeals process.

Structure and governance of assessment of need

The Health and Care Act 2022 created Integrated Care Boards and Integrated Care Partnerships who are responsible for commissioning and funding local health and social care services within local authorities.(65) The social services departments of local authorities have a duty under the Children Act 1989 to carry out assessments of need on request from parents or caregivers for 'children in need', which includes children with disabilities, and their carers.(66) The statutory guidance *Working Together to Safeguard Children* (2023) requires local authorities to set out their process for such assessments and their eligibility criteria for services. Importantly, there are additional types of assessment of children who need support. Further detail on these assessments is set out in Table 1. Oversight of local authorities and children’s services is provided by the Care Quality Commission (CQC) and Office for Standards in Education, Children's Services and Skills (Ofsted).

Scope of assessment of need

To meet the range of needs of children with disabilities, there are three types of assessments undertaken by local authorities, outlined below in Table 1. These are:

- Early Help Assessment
- Education, Health and Care needs assessment
- ‘Child in need’ assessment.

Table 1. Types of assessment

Early Help Assessment
An Early Help Assessment is a non-statutory assessment designed to provide the right support before a small need grows into a larger one. They are conducted by the social services departments of local authorities. A parent or guardian may request an assessment, or a professional can recommend the child or family. Early help is for families with children and young people of any age.
Education, Health and Care Needs Assessment
Under Part 3 of the Children and Families Act 2014, schools and local authorities have an obligation to identify and assess Special Educational Needs and Disabilities (SEND). A local authority can be requested to provide an Education, Health and Care (EHC) assessment where a young person up to 25-years-old needs higher levels of support than is available through standard education needs support provided by schools. If appropriate, this will result in an EHC plan. Under the Special Educational Needs and Disability Regulations 2014, the local authority must comply with a request for an assessment unless it believes, upon examining evidence, that it is not necessary.(67) This determination can be appealed to the SEND Tribunal. Health and social care needs are included in this assessment insofar as they relate to education.
‘Child in need’ Assessment
A ‘child in need’ assessment is carried out under Section 17 of the Children Act 1989.(66) Local authority social services have a statutory duty to safeguard and

promote the welfare of ‘children in need’ and their families. Under Section 17, a child under 18-years-old is in need if:

- he or she needs the support of local authority services to achieve or maintain a reasonable standard of development or health
- he or she needs the support of local authority services to prevent the impairment of or further harm to their development or health
- he or she has a disability.

Children aged under 18-years-old with disabilities have a right to an assessment under Section 17 of the Children Act. The local authority then has a duty to provide any services necessary to meet their needs. Under the 1989 Act, a child has a disability if they:

- are blind
- are deaf
- are non-verbal
- suffer from a ‘mental disorder of any kind’
- are ‘substantially and permanently handicapped by illness, injury or congenital deformity, or such other disability as may be prescribed.’

Assessment of need process

Local authorities have discretion in determining local protocols for assessment, for example, timelines for assessment, as well as setting eligibility within the limitations of statutory requirements, as set out in *Working Together to Safeguard Children*. Each local authority must provide information to the public on its procedures. This section outlines the assessment of need process for:

- Education, Health and Care needs assessment
- Early Help assessment
- ‘Child in need’ assessment.

Some local authority social services departments have a single point of access for all assessments types, in others requests are directed to a particular team, for example, a Children’s Disability Team or a Child in Need Team. Eligibility criteria for social care services may vary from one local authority to another. Local authorities may offer families the option of a personal or individual budget for services (‘self-directed support'), though families have the right to decline this and opt for services provided by the authority.

Education, Health and Care (EHC) Needs Assessment

Local authorities have an obligation to identify all children and young people in their area who have or may have Special Educational Needs (SEN) or a disability. Anyone can bring the needs of a child or young person who they believe has, or probably has, SEN or a disability to the attention of a local authority, early years providers and schools. The *SEND Code of Practice 0 to 25 Years*, which is statutory guidance under the Children and Families Act 2014, states that an EHC needs assessment must have regard to the views, wishes and feeling of the child or young person and the child's parents, and include them as fully as possible in decision-making.(62,68) The local authority must create an EHC plan for children and young people up to age 25, where they need higher levels of support than is available through standard education needs support provided by schools. The code of practice states that local authorities should adopt a key working approach, which provides children, young people and parents with a single point of contact to help ensure the holistic provision and coordination of services and support throughout this process.

When carrying out an assessment, the local authority must seek the following:

- advice and information from the child's parent or the young person
- educational advice and information from the head teacher or principal of their setting, or where this does not apply, from a person with experience of teaching children or young people with SEN
- medical information and advice from their treating health professionals
- psychological information and advice from an educational psychologist
- social care advice and information from or on behalf of the local authority
- from Year 9 onwards (approximately aged 13), advice and information related to provision to assist the child or young person in preparation for adulthood and independent living
- advice and information from any person requested by the child's parent or young person, where this is considered reasonable
- other advice as appropriate (for example, where a child or young person is detained in a Young Offender Institution, where they are a looked after child, or for children of members of the armed forces).(62)

Once a local authority has been asked to carry out an assessment, it must state within 16 weeks whether an EHC plan is required. The final EHC plan must be provided no more than 20 weeks from the date of request. An EHC plan describes the services that will be provided following the assessment and is legally enforceable through judicial review. Health and social care needs are included only insofar as they relate to education. Young people and parents of children with EHC plans have a right to request a personal budget, which may contain elements of education, social care and health funding. The child's parent or the young person must be given 15 calendar days to consider and provide views on a draft EHC plan and ask for a particular school or other institution to be named in it.

There is an annual review process for EHC Plans. The review considers:

- what progress has been made towards the agreed outcomes in the EHC plan
- whether any changes and or amendments may be required to the content of the EHC plan
- whether a personal budget is being reviewed or requested
- whether an EHC plan is still needed or have the agreed outcomes now been met.

The annual review process must be completed within 12 months of the EHC Plan or the date of the last annual review was completed. If the child is under five, the EHC Plan should be reviewed at least every three to six months, to ensure that the provision continues to be appropriate.(62)

The local authority must ensure that children, young people and parents are provided with information and advice on matters relating to SEN and disability. When carrying out their statutory duties under the Children and Families Act 2014, local authorities must do so with a view to making sure that services work together where this promotes children and young people's wellbeing or improves the quality of special educational provision. Local authorities and health bodies must have arrangements in place to plan and commission education, health and social care services jointly for children and young people with SEN or disabilities.

Early Help Assessment

An Early Help assessment can be provided at any stage of a child or young person's life, with the consent of parents or carers. The local Early Help assessment process is set out by the local safeguarding partners (health, local authorities and police). The process includes the appointment of a lead practitioner for each case. The assessment of need considers the needs of all members of the family. Where a child and family would benefit from co-ordinated support from more than one organisation or agency, there is a multi-agency assessment. *Working Together to Safeguard Children* outlines the elements of an early help assessment.(61) These should:

- be undertaken with the agreement of the child and their parents or carers, involving the child and family as well as all of the practitioners who are working with them
- take account of the child's wishes and feelings wherever possible, which could include providing advocacy support where this is needed
- take account of the child's age, family circumstances and extra-familial contexts and whether these factors are contributing to or preventing good outcomes
- take account of the needs of all members of the family as individuals and consider how their needs impact on one another, which includes needs relating to education, early years development, mental health and physical health, substance misuse, financial stability, housing, family relationships, domestic abuse and crime, as described in the Supporting Families Outcomes Framework, a set of indicators of successful outcomes measured at a family by family level(69)
- cover both presenting needs and any underlying issues, with the understanding that a family's needs can change over time, for example, when a child moves up to secondary school
- be based on facts, and explore and build on strengths
- be clear about the action to be taken and services to be provided
- identify what help the child and family require to prevent needs escalating, and
- provide the basis for any future assessments if they are needed, for example, under Sections 17 and 47 of the Children Act 1989.

Following the completion of an Early Help assessment, an action plan is prepared based on the information provided. This action plan sets out the services that need to be provided to meet the child's needs in the short-term, and also includes details of when the plan needs to be reviewed.

'Child in need' Assessment

A child with a disability is entitled to a statutory 'child in need' assessment; the local authority then has a duty to provide support to meet their needs. In practice these are predominantly conducted where a child is presenting with complex needs or where there is a safeguarding concern. In line with the requirements set out in *Working Together to Safeguard Children,* local authorities are directed to develop and publish local protocols for 'child in need' assessments. These set out arrangements for how cases will be managed once a child is referred into the local authority's children's social services. A local authority social worker should make a decision about the type of response needed within one working day of a referral being received, for example immediate protection and urgent action, assessment under Section 17 of the Children Act, or further specialist assessments. They must also acknowledge receipt of the referral. The maximum timeframe for completing the assessment is 45 working days from receipt of the referral. If it is not completed by then, the social worker should record the reasons for exceeding the time limit.

An assessment typically involves a social worker coming to the child's home to speak with the family. They should ask for information about the child, for example, sleeping patterns, eating habits, how the child communicates, and what activities they enjoy. Health professionals and the child's school may also be asked for information.(70) The local authority is encouraged to follow the detailed assessment framework set out in *Working Together to Safeguard Children*, this is a holistic approach to assessment under three dimensions, which are:

- the child's developmental needs
- the capacity of parents or carers and any other adults living in the household to respond to those needs, and
- the impact and influence of the family network and any other adults living in the household, as well as community and environmental circumstances.

There is a lead practitioner for each assessment and this role can be held by a range of professionals, including social workers. If practitioners identify specific needs during the assessment process, they do not need to wait until the assessment concludes before providing support or commissioning services to support the child and their family.

Among the underpinning principles are that; assessments should be child-centred; focused on action and outcomes for children; multi-agency and multi-disciplinary discussed with the child and their parents or carers; holistic in approach; explore the needs of all members of the family as individuals; and be a dynamic process, not an event. When undertaking an assessment of a child with a disability, *Working Together to Safeguard Children* states that the process should focus on the needs of the child and family, be strengths-based, and gather information to inform decisions on the help needed to:

- ensure the child achieves the best possible outcomes
- enable the child's family to continue in their caring role, where that is right for the child
- safeguard children in cases where there is abuse, neglect, and exploitation
- ensure that appropriate practical support is in place to enable disabled children and their families to thrive.

Local authorities can involve other public bodies, for example, health or education services, to help them perform the assessment, and a duty to co-operate exists under Section 27 of the Children Act 1989. In many local authority areas, a panel decides on the package of services that may be offered to the child and family, based on their assessed needs.(70) The local authority has a duty to provide or arrange services to meet those needs. The plan should give details of:

- what services will be provided
- for how long the services are needed
- what the local authority plans to achieve by providing the services
- what each person and agency is expected to do, and
- the date of the next review.

The care plan should be reviewed regularly to ensure services remain appropriate. There are no statutory timeframes for these reviews.

Local authorities might also offer a personal budget in lieu of services. They also have the power to charge for services they provide under the Children Act 1989 and the Chronically Sick and Disabled Persons Act and each local authority has its own charging policy and charges may be means-tested.(71)

Appeals process

All councils are legally obliged to have a formal complaints procedure. Local authorities are required to make information on complaints available to an applicant at the time of the assessment. If a person makes a complaint, the local authority should tell them whether it is going to consider the complaint through its own procedure, or under the statutory procedure for responding to complaints in children's social care services. The statutory procedure for complaints in children's social care services has three stages: local resolution (in 10 days by a local authority social services manager); investigation (in 25 days by a Customer Relations Team); and review panel hearing (managed by the Customer Relations Team and held within 30 days).(72) If the applicant is not satisfied with the response, they may take the complaint to the local government and Social Care Ombudsman.(73) If it decides it can legally deal with the complaint, the ombudsman has up to 12 months to provide a resolution.

There is a separate process for appeals following a SEND assessment. Once an EHC plan is received, the applicant has at least 15 days to comment. The applicant can challenge the local authority about:

- their decision to not carry out an assessment
- their decision to not create an EHC plan
- the special educational support in the EHC plan
- the school named in the EHC plan.

If this cannot be resolved with the local authority, it can be appealed to the Special Educational Needs and Disability (SEND) Tribunal.(74) The deadline for making appeals is two months from the date of the letter from the local authority giving their final written decision. If the circumstances are exceptional, it is possible to apply to extend the time.

In most cases the applicant will need to consider whether they want to go to mediation before they make an appeal. If they go to mediation or decide that they do not want to go to mediation, they will need a mediation certificate issued by a mediation provider before they can make an appeal. The applicant has two months to request a mediation certificate from the date of the letter from the local authority giving their final decision. The letter must give contact details for a mediation provider. This deadline cannot be extended by the mediation provider. They will then have an additional 30 days from the date of the mediation certificate to make an appeal to the SEND Tribunal.(75) The SEND Tribunal cannot deal with a case if the complaint is related to the way the local authority carried out the EHC assessment, or the length of time that it took.

3.1.3 Relevant legislation

This section outlines legislation relevant to assessment of need for children and young people. The central piece of legislation is the Children Act 1989; the Children Act 2004 is an update to the 1989 Act, promoting interagency co-operation. The legislation covered in this section is as follows:

- Children Act 1989
- Children Act 2004

- Children and Families Act 2014
- The Special Educational Needs and Disability Regulations 2014
- Chronically Sick and Disabled Persons Act 1970
- Care Act 2014
- The Care and Support (Assessment) Regulations 2014.

Children Act 1989

The Children Act 1989 is the key piece of legislation underpinning the child protection system in England and Wales.(66) The Act allocates duties to local authorities, parents, guardians and other agencies to ensure children are safeguarded and supported. A ‘child in need’ assessment under Section 17 of the Act encompasses the assessment of both child protection needs and the needs of children with disabilities. It requires local authorities to ascertain the child’s wishes and feelings regarding the provision of services with regard to safeguarding or promoting the child’s welfare.

Children Act 2004

The Children Act 2004 places an obligation on local authorities to promote interagency cooperation to improve the welfare of children, with a child protection focus.(76) It states that safeguarding partners for a local authority area must make arrangements to work together to identify and respond to the needs of children in the area. The Act established the Office of the Children’s Commissioner for England, a body responsible for promoting and protecting the rights of children.

Children and Families Act 2014

The Children and Families Act 2014 promotes the physical, mental health and emotional wellbeing of children and young people with special educational needs (SEN) or disabilities.(68) It outlines the functions of local authorities in supporting and involving children and young people, including in the assessment of education, health and care (EHC) needs and the provision of EHC plans. Section 25 of the Children and Families Act 2014 places a duty on local authorities to ensure integration between educational provision and training provision, health and social care provision, where this would promote wellbeing and improve the quality of provision for young people with disabilities and those with SEN.

The Special Educational Needs and Disability Regulations 2014

These regulations related to the Children and Families Act 2014 set out how local authorities should conduct an EHC needs assessment, what is to be taken into account, how decisions are made, the duty to co-operate, preparation of EHC plans, reviews, mediation and appeals.

Chronically Sick and Disabled Persons Act 1970

The Chronically Sick and Disabled Persons Act 1970 makes provisions for chronically sick and disabled persons.(77) It requires local authorities to inform them of available services, and to provide specific welfare services, for example, practical assistance in the home, holidays or with meals. It contains provisions on assessment regarding transition for children to adult care and support, but does not set out the nature of assessment.

Care Act 2014

Under the Care Act 2014, local authorities must carry out an assessment of adults in need of care and support.(78) The Act also sets out the next steps after assessment, and provisions for direct payments, deferred payments, continuity of care and support, safeguarding and independent advocacy. It also sets out requirements for the transition from children's services to adult care and support.

The Care and Support (Assessment) Regulations 2014

These regulations under the Care Act 2014 set out the broad terms for a child's assessment of need when transitioning to adult care and support.(79) Among their provisions are that a local authority must ensure the individual is able to participate in the process as effectively as possible; that it must provide the individual with information about the assessment process; and that it must consider the impact of the individual's needs on any person involved in their care and on any person the authority considers to be relevant.

3.1.4 Standards, guidance, frameworks, strategies and policies

There are no specific health and social care standards guiding assessment of need in England. Rather, there is statutory guidance for 'child in need' assessment and Early Help assessment as set out in the statutory guidance, *Working Together to Safeguard Children*. The *Special educational needs and disability code of practice: 0 to 25 years* outlines all the key stages in statutory education, health and care (EHC) needs assessment and preparing the EHC plan. At the time of writing this report, the most significant strategy is the *Special Educational Needs and Disabilities (SEND) and Alternative Provision (AP) improvement plan* (2023), which will see the creation of national standards for SEND provision by 2025. This section provides further detail on guidance, strategies and policies relating to assessment of need.

Guidance

In England, key guidance documents are in place that outline the principles of how assessment of need should be conducted. Of particular relevance is the statutory guidance *Working Together to Safeguard Children* and the *Special educational needs and disability code of practice: 0 to 25 years*.

Working Together to Safeguard Children (2023)

Working Together to Safeguard Children is the statutory guidance for multi-agency working to help, protect and promote the welfare of children. It outlines in detail the principles of Early Help and 'Child in need' assessment.(61) *Working Together to Safeguard Children* also provides guidance on the need for multi-agency assessment, timeliness, outcomes, involvement, and the processes for managing cases.

Special educational needs and disability code of practice: 0 to 25 years (2015)

This statutory guidance is related to Part 3 of the Children and Families Act 2014 and associated regulations. It explains the duties of local authorities, health bodies, schools and colleges to provide for those with special educational needs under part 3 of the Children and Families Act 2014. Principles underpinning the code of practice are that:

- the views, wishes and feelings of the child or young person, and the child's parents are taken into account
- the importance of the child or young person, and the child's parents, participating as fully as possible in decisions, and being provided with the information and support necessary to enable participation in those decisions
- the need to support the child or young person, and the child's parents, in order to facilitate the development of the child or young person and to help them achieve the best possible educational and other outcomes, preparing them effectively for adulthood.

The code of practice outlines all the key stages in statutory assessment and planning and preparing the EHC plan. It outlines when a local authority must carry out an EHC needs assessment and describes who must be consulted and provide advice as part of the assessment. It provides information on the statutory steps required as part of the EHC needs assessment and EHC plan, including timescales. It provides guidance on how to write an EHC plan, how to request a particular school, college or other institution and how to request and agree personal budgets, including sources of funding. It also outlines how to finalise and maintain an EHC plan, how to transfer an EHC plan and information is provided on review and re-assessment of EHC plans, and how to cease and disclose an EHC plan.

Children’s Social Care National Framework (2023)

The Children’s Social Care National Framework is statutory guidance developed in response to the *Independent Review of Children’s Social Care* (see Section 3.1.6 for further details of this review).(64,80) The purpose of this guidance is to set direction for the system and to bring together the best evidence available to support families and protect children. The guidance covers the purpose, principles for practice, and expected outcomes of children’s social care, including care and support for children with SEN or a disability who receive support under Section 17 of the Children Act 1989. The national framework builds on broader frameworks, such as the *Supporting Families Outcomes Framework*.(69)

The national framework defines the purpose of children’s social care as being to support children, young people and families, to protect them by intervening decisively when they are at risk of harm, and to provide care for those who need it so that they grow up and thrive with safety, stability and love. Its principles are that children’s welfare is paramount; their wishes and feelings are heard and responded to; that social care works in partnership with families; children are raised by their families or family networks wherever possible; there is multi-agency working and that local authorities consider economic and social circumstances which impact children and young people. Key enablers identified in the framework are multi-agency working; leadership; and a workforce that is equipped and effective.

There are four outcomes to be achieved by children’s social care:

- children, young people and families stay together and get the help they need
- children and young people are supported by their family network
- children and young people are safe in and outside of their homes
- children in care and care leavers have stable, loving homes.

The national framework will be supported by the Children’s Social Care Dashboard, which will bring children’s social care data together in one place to understand progress towards the outcomes of the national framework.(81)

Disabled Children and Young People up to 25 with Severe Complex Needs: Integrated Service Delivery and Organisation across Health, Social Care and Education (2022)

This National Institute for Health and Care Excellence (NICE) guideline covers support for children and young people with severe complex needs, from birth to 25 years.(82) The guideline is not mandatory, but practitioners and professionals are expected to take it fully into account when exercising their judgment, alongside the needs and preferences of individuals using their service. The guideline aims to encourage education, health and social care services to work together and provide more coordinated support to children and young people with disabilities, and their families and carers. It includes recommendations on identifying needs, for example, special educational needs and social care needs; considering when to involve other services; requesting an EHC needs assessment and supporting children and their families through assessment.

Care and Support Statutory Guidance

This statutory guidance relates to adult care and support under the Care Act 2014 and associated regulations.(83) At the time of writing, it was under review following the Health and Care Act 2022. Chapter 16 addresses transition assessments and the move from child to adult care and support services. It covers:

- when a transition assessment must be carried out
- identifying young people who are not already receiving children's services
- features of a transition assessment
- cooperation between professionals and organisations
- providing information and advice once a transition assessment is completed
- provision of age-appropriate local services and resources
- after the young person in question turns 18
- combining EHC plans with care and support plans after the age of 18
- continuity of care after the age of 18
- safeguarding after the age of 18
- ordinary residence and transition to higher education
- transition from children's to adult NHS Continuing Healthcare.

Strategies and policies

There are a number of strategies and policies in place in England focused on improving the lives of people with disabilities. The *National Disability Strategy* (2021) sets out the actions the government will take to improve the everyday lives of people with disabilities. The strategy outlines targeted action to support disabled children in education, as well as broader action, such as changing perceptions, which will benefit disabled children as well as disabled adults. It is important to note that there is no explicit reference to assessment of need in the strategy.(84) *Children's Social Care: Stable Homes, Built on Love* (2023) is an implementation strategy to transform the experiences and outcomes of children and families who need support from children's social care.(85) As of December 2023, the following steps had been taken towards meeting this strategy:

- the national kinship strategy was published – Championing Kinship Care to set out support for family networks providing loving and stable homes to children
- a new children's social care national framework was published to set out the purpose, principles and outcomes that should be achieved in children's social care
- updates were made to the Working Together to Safeguard Children guidance, which sets out how to safeguard and promote the welfare of children
- a data strategy was published to set out long-term plans to transform data in children's social care
- £8.5 million was investment for fostering, to ensure the right homes for children.(61,86,87,88)

The most significant strategy in place in relation to assessment of need is the *Special Educational Needs and Disabilities (SEND) and Alternative Provision (AP) improvement plan* (2023), under which the government is developing national standards on SEND, with an aim of publishing a significant proportion of the standards in 2025.(89) It will also review social care legislation relating to children with a disability to improve clarity for families about the support they are legally entitled to. The plan also proposes to establish statutory local SEND and alternative provision partnerships. These will bring together partners across education, health, mental health and social care, to work collaboratively to meet statutory responsibilities. These partnerships will be responsible for undertaking a joint needs assessment and producing a strategic local inclusion plan (LIP) for local delivery, including setting out the provision and services that should be commissioned in line with the national standards. Among further actions are to:

- standardise the templates and processes around EHC plans to improve consistency and best practice
- digitise EHC plans, to reduce administrative burden and improve the ability to monitor the SEND system
- introduce the use of local multi-agency panels to improve parental confidence in the EHC needs assessment process

- publish guidance to support effective transitions between all stages of education, and into employment and adult services.

3.1.5 Regulation, monitoring and inspection of assessment of need

The Office for Standards in Education, Children's Services and Skills (Ofsted) and the Care Quality Commission (CQC) monitor and inspect the effectiveness of the local area partnership's arrangements for children and young people with special educational needs and or disabilities (SEND), including assessment of need. Ofsted is a non-ministerial department which both inspects and regulates local authorities providing care for children and services that provide education, social care and skills for young people. To inspect local authorities, the framework it primarily uses is the *Inspection of Local Authority Children's Services* (ILACS).(90) The CQC is the independent regulator of child and adult health services and adult social care in England. It works towards ensuring that health and social care services are delivered safely, effectively and with a high degree of quality of care. The CQC registers care providers who meet the required regulations and monitors these services through inspections.

Education, Health and Care Needs Assessment

Ofsted and the Care Quality Commission (CQC) jointly carry out inspections of local area arrangements for children and young people with SEND. Requirements are set out in the *Area SEND inspections framework and handbook*.(91) The framework sets out the purposes and principles of inspection and its statutory basis, along with the inspection approach, model, frequency and timing. The handbook sets out the evaluation criteria that inspectors use to make judgements, and examples of the kinds of evidence they gather and activities they carry out to evaluate the local area's arrangements for children and young people with SEND. It includes information about the inspection process before, during and after the inspection.

Inspectors evaluate the impact of the local area partnership's SEND arrangements on the experiences and outcomes of children and young people with SEND, including the extent to which:

- children and young people's needs are identified accurately and assessed in a timely and effective way
- children, young people and their families participate in decision-making about their individual plans and support
- children and young people receive the right help at the right time
- children and young people are well prepared for their next steps, and achieve strong outcomes

- children and young people are valued, visible and included in their communities.

Where there are widespread and or systemic failings, a monitoring inspection is carried out within 18 months and the next full area SEND inspection takes place within approximately three years (where there are positive results, full area inspections are held every five years). The local area partnership must submit a priority action plan to address the identified areas for action.

With regard to assessment of need, inspectors take account of the following, as set out in the *Area SEND inspections framework and handbook*:

Children and young people's needs are identified accurately and assessed in a timely and effective way

- children and young people are accurately identified as having special educational needs and or disabilities
- children and young people's needs are identified in a timely way, to prevent needs from escalating
- practitioners assess the strengths and determine the aspirations of the child or young person alongside their individual needs
- the criteria for carrying out assessments of need and for accessing services and support are understood, and the application of these criteria improves outcomes
- timely referrals are made to other services and agencies, where necessary.

Children, young people and their families participate in decision-making about their individual plans and support

- children and young people access impartial information, advice and support that enable them to make informed choices about their future
- children, young people and families are supported to understand their rights, make choices and contribute to decision-making about their plans and support
- children and young people understand their plans and support, including intended outcomes, and why some changes are not possible.

Children and young people receive the right help and support at the right time

- plans are developed and support is provided in a timely way, and meets children and young people's needs
- children and young people receive support based on their identified needs when they are awaiting assessment
- plans and support are coordinated within and, where necessary, across providers and services, and are based on a shared understanding of the child or young person
- plans and support are regularly reviewed and updated to reflect changes in children and young people's skills, independence, understanding and other factors in their lives, including reduced support in line with reduced need where appropriate
- the wider needs of the child or young person's family are considered, and barriers to learning and participation are addressed.

The framework also includes requirements on transitions and preparing for greater independence and adulthood, as well as supporting the inclusion of children and young people with SEND in their communities.

Child in need assessments

Ofsted, the CQC and His Majesty's Inspectorate of Constabulary, Fire and Rescue Services (HMICFRS) carry out Joint Targeted Area Inspections (JTAIs) of the multi-agency response to children and families who need help. The CQC have developed guidance on these which are carried out under Section 20 of the Children Act 2004.(92) Among other things, inspections evaluate:

- how effectively each agency contributes to the multi-agency response, including early decision-making across early help, child in need and child protection
- the timeliness of help and support, preventing children's needs and risks from escalating
- access to a sufficient range of effective local services
- that assessments are child-focused, comprehensive and timely.

3.1.6 Findings from reviews

The Office for Standards in Education, Children's Services and Skills (Ofsted) and the Care Quality Commission (CQC) publish annual reports on their inspections of services. The government also releases annual statistics on children in need in

England, including assessments completed by children's social care services. The *SEND Review: Right Support, Right Place, Right Time* and the *Independent Review of Children's Social Care* have informed recent and upcoming reforms in Special Educational Needs and Disabilities (SEND) and social care provision. The reviews included in this section are:

- Children in Need: Reporting Year 2023
- The Independent Review of Children's Social Care (2022)
- Annual Report of His Majesty's Chief Inspector of Education, Children's Services and Skills 2022/23
- The SEND Review: Right Support, Right Place, Right Time (2022).

Children in Need: Reporting Year 2023

This annual release from the children services statistics team in the Department of Education contains statistics on children in need in England. It includes statistics on child protection plans, referrals to children's social care services and assessments completed by children's social care services. In 2023, the average duration of a child in need assessment process was 33 days, an increase from 32 days in 2022, within the maximum 45 day timeframe set out in *Working Together to Safeguard Children* which refers to conclusion of the assessment 'such that such that it is possible to reach a decision on next steps'.(61,93) Assessments where the child's primary need was caused by disability or illness comprised 8% (32,790) of child in need assessments.[§]

The Independent Review of Children's Social Care (2022)

This independent review looks at the needs, experiences and outcomes of children supported by social care services in England. The review collected information from those with lived experience through a public Call for Advice and a Call for Evidence to ensure access to the latest research. The review team met 2,000 people with lived experience of children's social care, and 2,800 people with professional experience of children's social care.

The review proposed a radical reset of children's social care. It proposed introducing one category of 'Family Help' to replace targeted Early Help and Child in Need work, which would be delivered by multi-disciplinary teams. It also recommended a strengthened child protection system; unlocking the potential of family networks by bringing wider family members and friends into decision making; reform to the care

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[§] In 2021/22 around 11% of children in the UK had a disability. Esme Kirk-Wade. UK disability statistics: prevalence and life experiences. House of Commons Library, 2023. https://researchbriefings.files.parliament.uk/documents/CBP-9602/CBP-9602.pdf market through the establishment of Regional Care Cooperatives; five ambitious ‘missions’ for care experienced people which encompass loving relationships, quality education, a decent home, fulfilling work and good health; better workforce support; and the creation of a National Children’s Social Care Framework to set the direction and purpose for the system.

In regard to assessments, this review argued that they should be flexible and tailored to a family’s individual problem, particularly in the case of families of children with disabilities where ‘one size fits all’ assessments are overly intrusive, not tailored enough to the needs of families, and not well aligned with the framework for adult social care.(64) It further recommended that timescales for assessment be removed from *Working Together to Safeguard Children* (with safeguards against delays) to allow more flexibility in assessment according to need, and to avoid sending a message that assessment is a single, time-limited action.

The review noted the struggles of families of children with disabilities to access support and their frustration navigating services. It stated that the recommendations on ‘Family Help’ should provide a step change in how children with disabilities and their families experience children’s social care: reducing the stigma of asking for help; increasing the intensity of support; setting clearer eligibility for support; and reducing handovers between services.

The review further recommended that the Law Commission undertake a review of children’s social care disability legislation to bring more coherence to this disparate collection of legislation. It also highlighted children’s experiences of transitions into adult social care, recommending that there be an extension of disabled children’s teams for children and young people aged 0-25. Finally, it recommended improving the strategic integration of children’s social care with the SEND system.

Regarding inspection, it recommended that Ofsted inspection should be reformed to increase transparency in how judgments are made, ensure inspection applies a rounded understanding of being 'child focussed', and ensure inspection supports the proposed reforms. It also recommended strengthening intervention powers of Ofsted.

Annual Report of His Majesty’s Chief Inspector of Education, Children’s Services and Skills 2022/23

The 2022/23 Ofsted annual report noted that pressure on the SEND system has increased due to rising numbers of children and young people with SEND.(94) The report finds that many children, young people and families are experiencing delays in access to services, particularly to wider health and therapeutic services, such as speech and language therapy and mental health services. Local authorities were found to be struggling to meet demand for SEND assessments and follow-on services. These delays are harming the quality of specialist educational provision, which relies on external professional expertise and services to support its pupils.

Between January and August 2023, Ofsted and CQC inspected 16 local area partnerships. In five local area partnerships, the reports found that SEND arrangements typically led to positive experiences and outcomes for children and young people. In six areas, it was noted that SEND arrangements led to inconsistent experiences and outcomes. Five areas were found to have widespread and or systemic failings.

Inspections under the new Area SEND Inspections Framework are showing many of the same concerns as under the previous framework.(91) Most significantly, families continue to experience long waiting times for some assessments and support, such as child and adolescent mental health services (CAMHS), educational psychology and speech and language therapy. The increase in education, health and care (EHC) plans is having a negative impact on health and education services. The Department of Education has reported that services such as educational psychology are struggling to deal with the volume of EHC plan referrals, which is delaying access to other essential services.

The SEND Review: Right Support, Right Place, Right Time (2022)

The SEND Review noted inconsistencies in how needs are met and confusion in families on what to expect from local settings.(63) Children and young people's needs were identified late or incorrectly, with needs escalating. The review reported that this had led to increased requests for EHC plans and significant delays in accessing support. Among its recommendations, it proposed a new national SEND and alternative provision system and nationally consistent standards for how needs are identified and met. At the time of writing, national standards for SEND provision are under development in order to deliver a nationally consistent education, health and care plan process.

3.1.7 Key findings

In England, responsibility for the delivery and organisation of assessment of need lies with local authorities. This can be an 'Early Help' assessment, a statutory 'child in need' assessment – generally used where a child has more complex disabilities – or a statutory education, health and care (EHC) needs assessment, where a child needs more support than is available through special educational needs supports. These assessments are holistic, multi-agency and child-centred, and where a child in need plan or an EHC plan is required, the local authority has a duty to provide services. Both statutory assessments have timeframes that they must be completed in, though the *Independent Review of Children's Social Care* has called for more flexibility in child in need assessments, particularly to accommodate children with disabilities. It is not necessary for an assessment to be completed before beginning to deliver services.

The Office for Standards in Education, Children's Services and Skills (Ofsted) and the Care Quality Commission (CQC) jointly carry out inspections of local area arrangements for children and young people with special educational needs and or disabilities (SEND), and these inspections are led by Ofsted. In regard to Early Help and child in need assessments and care plans, Ofsted, the CQC and His Majesty's Inspectorate of Constabulary, Fire and Rescue Services (HMICFRS) carry out Joint Targeted Area Inspections (JTAIs) of the multi-agency response to children and families who need help.

A key lesson for Ireland is the holistic nature of assessments. For example, in the case of child in need assessments, the assessment incorporates the child's developmental needs, the caregivers' capacity, and the influence of the environment in which the child is living.

It is also notable that it is statutory guidance which sets out the underlying principles of child in need and EHC needs assessments and plans, although local authorities do have discretion in developing their own processes around assessment, once it is in line with the guidance. There is legislation on multi-agency working (for example, a duty to co-operate under Section 27 of the Children Act 1989) and there are legislative provisions for the transition from child to adult services (Care and Support (Assessment) Regulations 2014). These legal frameworks strengthen the holistic nature of assessment, the processes for multi-agency working, and place duties on local authorities to provide services and supports as well as assessments.

Monitoring and inspection does not look at assessment of need in isolation. Joint inspections of area SEND arrangements by Ofsted and the CQC look at systems that are in place, rather than individual practitioners or providers. These inspections build an overall picture of a child's experience and their journey through the system over a two-year period, encompassing health, social care and education. In areas of best practice, these inspections show that services and supports are needs led, rather than dependent on assessment or diagnosis.

3.2 Scotland

This section describes the organisation and delivery of assessment of need services in Scotland. The section is set out under the following headings:

- overview of assessment of need
- the model of service
- relevant legislation
- standards, guidance, frameworks, strategies and policies
- regulation, monitoring and inspection of assessment of need
- findings from reviews
- key findings.

3.2.1 Overview of assessment of need

In Scotland, people with disabilities have a statutory entitlement to an assessment of their needs and the provision of services to support their welfare. Under the Children (Scotland) Act 1995, local authorities have a duty to assess both people aged 0-18 with disabilities and their carers to determine the needs of the child or young person, and the carer's ability to provide care for them.(95) Legislation also sets out the duties of local authorities to support children and their families and to intervene when the child's welfare requires it. It also sets out the requirement to involve the person in their assessment, their right to dignity and to participation in the community. In 2022, Scotland’s population was estimated to be 5.4 million people; people with a disability accounted for 26% of the population.(60,96)

The Scottish Government sets policy for health and social care in Scotland. Local authorities are responsible for assessment of need and the delivery of social care services, while health services are delivered by local health boards and national special health boards under the remit of NHS Scotland. Assessments of need are holistic and are conducted under the *Getting It Right For Every Child* (GIRFEC) approach.(97) Once an assessment is completed, a social worker draws up a ‘child in need care plan’. Education authorities carry out assessments of special educational needs, if needed they write up a report outlining the results of the assessment and what supports are required for the child’s education.

While there are no standards specific to assessment of need, the *Health and Social Care Standards: my support, my life* (2017), developed by the Scottish Government, set out what people should expect when using health, social care or social work services in Scotland.(98) The Care Inspectorate is the regulatory body for care services. It inspects quality of care in Scotland to ensure it meets high standards and supports services to make positive changes. The Care Inspectorate undertakes inspections of social care and social work services provided by local authorities, as well as day care and support services.(99) Healthcare Improvement Scotland regulates and inspects healthcare services, and works with the Care Inspectorate on inspection of integrated health and social care services.

At the time of writing, the Scottish Government is in the process of planning a National Care Service (NCS), this will move responsibility for care services from local authorities to the Scottish Government ministers by 2026.(100) The Nuffield Trust notes that having a national agency driving commissioning, coordination across care organisations and integration of community health and social care may also address issues in consistency and quality of services across Scotland.(101) At the time of writing it is unclear how this will impact on the delivery of assessment of need and related services by local authorities.

3.2.2 The model of service

In Scotland, responsibility for the delivery and organisation of assessment of need lies with the social care departments of local authorities. This section sets out the model of service under the following headings:

- structure and governance of assessment of need
- scope of assessment of need
- assessment of need process
- appeals process.

Structure and governance of assessment of need

The Scottish Government has overall authority for health and social care services. There are 32 local authorities (councils) in Scotland which deliver social services, and they have a statutory duty to conduct assessment of need for children, as set out under the Children (Scotland) Act 1995. Assessment of need for children may be carried out, for example, by a Children's Disability Team or a Child in Need team, as appropriate to the needs of the child. A Children's Disability Team serves children with disabilities who have complex needs, while a Child in Need team more broadly serves children in need of support or at risk of harm. Each local authority determines its own pathway for managing requests for assessments.

At the time of writing, the Scottish Government is in the process of planning a National Care Service (NCS).(100) The NCS will move responsibility for care services from local authorities to Scottish Government ministers by 2026, marking a radical change in the organisation of social care.(101) It will set standards and direction for the social care system at a national level, planning and commissioning primary care and community health services. By supporting the Fair Work Convention, an independent advisory body which aims to improve terms and conditions for the care workforce, the NCS will also address issues around staff recruitment and retention.(102)

Scope of assessment of need

Under Sections 23-24 of the Children (Scotland) Act 1995, a local authority has a duty, when asked by a parent or guardian, or on foot of a referral, to assess children or young people aged under 18 with disabilities and their carers to determine:

- the needs of the child or young person
- the carer's ability to provide care for them.(95)

Section 17 of the Act states that a child is in need if:

- he or she is unlikely to achieve or maintain, or to have the opportunity of achieving or maintaining a reasonable standard of health or development unless they are provided services by a local authority
- his or her health or development is likely to be significantly impaired, or further impaired, unless such services are provided
- he or she is disabled.

The Children (Scotland) Act 1995 Regulations and Guidance state that the duty to safeguard and promote the welfare of children in need falls upon the local authority as a whole, and encompasses social work services, education, housing and any other relevant services required to safeguard and promote the welfare of such children.(103)

Assessment of need process

A parent or guardian can make a request for assessment, or they can request a referral from, for example, a child’s school, general practitioner (GP) or any other professional involved in the care of the child. A social worker from within the local authority contacts a family to carry out an initial assessment to help children’s services identify whether or not the child is in need, what services may be needed and whether the case is urgent. After this they may decide to carry out a core assessment, which is more thorough.(104) There are no statutory timeframes for assessment.

While local authorities determine their own method of assessment, Section 23A of the Children (Scotland) Act 1995 stipulates that the local authority must assess the wellbeing of a child or young person with reference to the SHANARRI indicators set out under the Children and Young People (Scotland) Act 2014. These indicators are safe, healthy, achieving, nurtured, active, respected and responsible, included.(105)

Many local authorities use the *Integrated Assessment Framework* (IAF) to assess the needs of children who require support from multiple agencies.(106) The IAF is part of the Scottish Government's *Getting It Right For Every Child* (GIRFEC) policy, which is embedded across children's services: health, education, welfare and youth justice. GIRFEC provides a consistent framework and shared language for promoting, supporting, and safeguarding the wellbeing of children and young people. There are three main domains in an integrated assessment under GIRFEC:

- the child's developmental needs
- parents' or caregivers' capacity to respond to those needs
- wider family and environmental factors.

Detail on the conduct of assessments is set out in the Regulations and Guidance on the Children (Scotland) Act 1995 (see Section 3.2.3). The regulations stipulate that assessments 'should' be strengths based; that they may vary in length depending on the complexity required; and that they should take into account families' views and preferences. The regulations also stipulate that local authorities should consider the contribution which other agencies, for example, health or education, might make to the assessment or services provided.

The regulations further state, that if the local authority makes a determination to provide services to a child, they should make a plan with the family, which should form the basis of a written agreement outlining the nature of the service or services to be provided. This plan should set out how long these services may be required for, the objectives of the plan and the roles, responsibilities and tasks of all those involved in the plan, including other agencies and family members.(103) The plan is normally coordinated by the social work department. The plan and agreement should take account of the child's view and note any areas of disagreement between the social work department, the family or other agencies. It should also specify how and by whom any problems or dissatisfaction will be dealt with if these arise. The regulations set out that the plan should be reviewed regularly, however no statutory timeframe is set for review.

While local authorities reference the SHANNARI indicators, eligibility criteria for services vary by local authority.(107) Where it is assessed that support is needed, a person in need must be offered four options by the local authority:

- a direct payment and the person arranges support or services themselves
- the person decides and the local council arranges support
- the local council decides and arranges support
- a mixture of the three above.

The Social Care (Self-directed Support) (Scotland) Act 2013 specifies that a child over 16 has the right to make decisions about their own support.(108) Below the age of 16, the person with responsibility for the child, known as the ‘appropriate person’, should be involved in decisions about the child’s support and the choice of the four options.

Partnership with children and their parents is considered important in planning and delivering services. The Regulations and Guidance for the Children (Scotland) Act 1995 require that:

- they have sufficient information, both orally and in writing, to make informed choices
- they should be aware of the consequences of decisions they may take
- they should be actively involved where appropriate in assessments, decision-making meetings, care reviews and conferences
- they should be given help to express their views and wishes and to prepare written reports and statements for meetings where necessary
- professionals and other workers should listen to and take account of parents and carers' views
- there should be clear and accessible means for families to challenge decisions taken by professionals and to make a complaint if necessary
- administrative arrangements should take account of the needs of children and their parents, for example, in deciding the location and timing of meetings to ensure their attendance, providing a welcoming and comfortable environment.

Appeals process

Section 5B of the Social Work (Scotland) Act 1968 requires local authorities to establish local procedures for considering complaints about the discharge of any of their social work functions.(109) A person can also make a complaint to the Care Inspectorate, the independent body responsible for regulating care services. In some cases, the Care Inspectorate will recommend that a person use the local authority complaints procedure first, but this is not compulsory. If the person is unhappy with the Care Inspectorate's decision, a complaint can be made to the Scottish Public Services Ombudsman.

3.2.3 Relevant legislation

The primary legislation in respect of assessment of need for children with disabilities is the Children (Scotland) Act 1995 and associated regulations. Other relevant pieces of legislation are the Children and Young People (Scotland) Act 2014, which introduced the Getting It Right For Every Child (GIRFEC) framework, and the Social Care (Self-directed Support) Act 2013, which introduced the option of direct payments for arranging care and support. This section covers the following legislation:

- The Children (Scotland) Act 1995
- The Children (Scotland) Act 1995 Regulations and Guidance: Volume 1 Support and Protection for Children and Their Families
- The Children and Young People (Scotland) Act 2014
- The Social Care (Self-directed Support) Act 2013.

The Children (Scotland) Act 1995

The Children (Scotland) Act 1995 is centred on the needs of children and their families and defines both parental responsibilities and rights in relation to children. It sets out the duties and powers available to public authorities to support children and their families and to intervene when the child's welfare requires it. Section 23 of the Act places a duty on local authorities to carry out an assessment of the needs of a child with a disability, where requested. In determining the needs of the child, the local authority must take into account care provided by an adult or young carer, and the views of the parent or guardian, and of the child.

The Children (Scotland) Act 1995 Regulations and Guidance: Volume 1 Support and Protection for Children and Their Families

Chapter 6 of the regulations provides the legal framework for assessment, and the services and support provided to children with disabilities, children affected by disability and their families. The regulations state that local authorities should set their own standards covering the services they arrange and deliver, including standards for screening and assessment. On the nature of the assessment, they state that the local authority should gather sufficient information to enable a judgment to be made about those aspects of the child's health, welfare or development that require some help, and what services, if any, they should offer.

The regulations and guidance recognise that assessments vary in the degree of complexity and information required, and in the time they take to complete. They state that an assessment should focus on a family's strengths and skills, as well as difficulties. They note that some assessments might take relatively little time and can be carried out by a social worker collecting and evaluating information from a small number of sources, while others may be more complex and may take considerable time, involving meetings with family members and consultation and meetings with other professionals. The results and outcomes of assessments should be written down and a record made available to families.

The regulations and guidance also indicate that in assessing children's needs, local authorities should take into account families' views and preferences, and consider the contribution which other statutory and voluntary agencies, for example health and education, might make to the assessment or services provided. Social work departments should make arrangements with local education departments, Health Boards and NHS Trusts, and primary care teams, for sharing information, joint assessment and provision of health, education and social work services in individual cases, in the light of the requirements for collaboration under the Act.

Assessments of children in need with disabilities should be, wherever possible, combined with those under other legislation such as education or children at risk, and information gathered by different local authority departments can be used for multiple purposes. The regulations and guidance note that established systems for formal assessment of special educational needs under the Education (Scotland) Act 1980 require collaboration between education, health and social work professionals and the involvement of parents and children and young people.(110) These should contribute significantly to assessments of children with disabilities by social work departments and may be used as a foundation for further joint decision-making about families' wider needs for social support and services.

The Children and Young People (Scotland) Act 2014

This Act put the United Nations Convention on the Rights of the Child (UNCRC) into Scottish law and requires Scottish Ministers and public bodies to report on their actions to support children’s rights. It placed the GIRFEC framework into law, including the eight SHANARRI indicators of wellbeing, which must be referred to when assessing children’s needs and planning and delivering services to meet those needs.

The Social Care (Self-directed Support) Act 2013

The Self-Directed Support (SDS) Act makes provisions relating to the arrangement of care and support, in order to provide more choice and control to both children and adults. Sections 1 and 2 of the Act set out general principles in relation to assessment, including the involvement of the person, and their right to dignity and to participation in the community.

3.2.4 Standards, guidance, frameworks, strategies and policies

Scotland has an overarching set of health and social care standards in place outlining what people should expect when using health, social care or social work services. Of particular relevance to assessment of need is the statutory guidance Getting It Right For Every Child (GIRFEC); this outlines the principles used in assessing the wellbeing of children and young people. This section provides further detail on standards, guidance, policies and strategies relating to assessment of need.

Standards

While there are no specific health and social care standards guiding assessment of need in Scotland, there are overarching standards for health and social care services: *Health and Social Care Standards: My Support, My Life*.(98) These standards set out what people should expect when using health, social care or social work services in Scotland. All services and support organisations, whether registered or not, are advised to use the standards as a guideline for how to achieve high quality care. Inspection frameworks used by the Care Inspectorate reflect the health and social care standards.(111)

Scotland has statutory guidance on the GIRFEC assessment of wellbeing, and on assessment for self-directed support, as well as a Framework of Standards on Self-Directed Support (SDS) for local authorities.

Getting It Right For Every Child (GIRFEC) - Statutory Guidance - Assessment of Wellbeing 2022 – Part 18 (Section 96) of the Children and Young People (Scotland) Act 2014

This statutory guidance clarifies how the eight wellbeing indicators (SHANARRI) are used in assessing the wellbeing of children and young people and explains what wellbeing is in the context of the Children and Young People (Scotland) Act 2014. The Act refers to assessment of an individual child or young person to determine whether ‘their wellbeing is being, or would be, promoted, safeguarded, supported, affected or subject to an effect’ (Section 96(1)). The GIRFEC guidance states that an assessment of wellbeing must seek to identify all the factors in the child or young person’s life which may be affecting their physical, mental or emotional wellbeing. This helps to establish how best to support the child or young person when they experience difficulties. It includes, but is not limited to, recognising individual, family and community strengths, as well as difficulties they face such as poverty, health, disability, inequalities or communication needs, and how these needs might be met to improve wellbeing. It should also recognise the extent to which a child or young person is able to enjoy their rights, and any support needed to enable this.

The guidance sets out that where a child or young person requires the support of a specialist service, the specialist practitioner must have individual assessment tools to analyse information about a specific area of their needs. These specialist assessments form part of the holistic assessment of wellbeing where required, together with input from children, young people, families and others, and should be considered in the context of the child or young person's life at home, in a learning environment and in the wider community.

Statutory Guidance to accompany the Social Care (Self-directed Support) (Scotland) Act 2013

Section 6 of the statutory guidance accompanying the 2013 SDS Act covers assessment, eligibility and review. The statutory guidance emphasises a human rights-based approach to assessment and care and support planning. It notes that under Sections 6 and 17 of the Act, the authority must take reasonable steps to help the supported person to play a full part in their assessment, to understand the various choices available to them and to decide how and in what ways they would like to arrange their support.

Self-Directed Support Framework of Standards, Including Practice Statements and Core Components (2021)

This framework consists of a set of standards (including practice statements and core components) written specifically for local authorities to provide them with an overarching structure, aligned to legislation and statutory guidance, for implementation of the SDS approach and principles.

Implementation of standards

Quality frameworks developed by the Care Inspectorate set out key elements that support services to self-evaluate their performance in regard to the high level *Health and Social Care Standards*.(111) Many local authorities use elements of the *Quality Framework for Children and Young People in Need of Care and Protection* to help evaluate their services for children with disabilities.(112)[**] This framework has 10 key indicators for self-evaluation, including 'Key performance outcomes,' 'Impact on children, young people and families' and 'Delivery of key processes.'

Self-evaluation for improvement broadly focuses on answering three key questions:

[**] This information was provided by subject matter experts from Care Inspectorate Scotland, interviewed on 19 March 2024 to inform this research report.

- How good are we now?
- How do we know?
- What we plan to do next?

At the time of writing, Social Work Scotland is developing SDS practice resources, including an SDS Toolkit for Practitioners and a self-evaluation framework and practice guidance.(113)

Guidance

There is guidance for practitioners on conducting an assessment under the GIRFEC model, and in delivering self-directed support once needs are identified. This section details the following guidance:

- Getting It Right For Every Child (GIRFEC) Practice Guidance 1 - Using the National Practice Model (2022)
- Self-directed Support: Practitioners Guidance (2014)

Getting It Right For Every Child (GIRFEC) Practice Guidance 1 - Using the National Practice Model (2022)

This practice guidance supports practitioners and managers to embed and implement GIRFEC into their everyday practice.(114) The National Practice Model provides a framework to structure and analyse information consistently in order to understand the strengths and challenges faced by a child or young person, as well as their needs, and to consider the scaffolding of support that may be required. It also supports full participation of children, young people and their families in gathering information to assess what support they may need, and to make joint decisions to plan and deliver that support.

There are five key GIRFEC questions that practitioners should ask themselves when considering a child or young person's wellbeing needs:

1. What is getting in the way of this child or young person's wellbeing?
2. Do I have all the information I need to help this child or young person?
3. What can I do now that is needed and appropriate to help this child or young person?
4. What can my agency or organisation do now to help this child or young person?
5. What additional help, if any, may be needed from others?(114)

The guidance states that in the GIRFEC approach, any child or young person who requires additional support should have a plan to address their needs and improve their wellbeing. This could be a single-agency plan or a multi-agency plan co-ordinated by a lead professional. Under GIRFEC, every child will have a named person within universal services[††] of health and education to liaise with; their role is to act as the first point of contact for children and families.(115) Where a child needs involvement from more than one agency, a lead professional will be involved.

Self-Directed Support: Practitioners Guidance (2014)

This provides a guide for all practitioners who have responsibilities under the 2013 SDS Act on how to effectively deliver on their duties and responsibilities with people who need, or may need support.(107) It is primarily aimed at local authority practitioners. It offers practical examples of how the Act translates into practice, including a broad 'how to guide' in relation to complex assessment and support planning. With regard to children and young people, it states that a young person over 16 has the right to make decisions about their own support, unless questions of capacity have been identified. Below the age of 16, the person with responsibility for the child should normally be involved in decisions about the child's welfare and support. A child aged 12 or over is presumed to be of sufficient age and maturity to express a view and this should be taken into account. At any age, the child's view is central to assessment, planning and decision making.

Strategies and policies

There are a number of disability strategies in Scotland. *A Fairer Scotland for Disabled People* (2016) sets out Scotland's delivery plan for the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) up to 2021.(116) While it did not contain any actions specific to assessment of need, a key ambition was to support services that meet the needs of people with disabilities, particularly by investing in self-directed support. The plan also committed to developing a 'national framework for families with disabled children and young people.' The framework was developed in the form of a guide to make it easier for children and families to understand government policy, know their rights and learn what services they are entitled to.(117) There are further government strategies on improving prospects for people with learning disabilities and on autism.(118,119) In relation to assessment of need, this section outlines the following policies in more detail:

- Getting It Right For Every Child (GIRFEC) (2022)

[††] Universal services aim to meet a set of core needs and include family planning, parenting capacity and or skills, mental health of both infant and parents, good oral health, nutrition, childcare, education, family learning, employability, play and leisure.

- Self-Directed Support: Improvement Plan 2023 to 2027 (2023).

Getting It Right For Every Child (GIRFEC) (2022)

This is the national approach in Scotland to improve outcomes and support the wellbeing of children and young people, by offering the right help at the right time from the right people. GIRFEC is embedded across children's services: health, education, welfare and youth justice. It is a strengths-based approach and its core principles focus on placing the child or young person and their family at the heart, and promoting choice, working together with families to enable a rights respecting, strengths based, inclusive approach, and understanding wellbeing as being about all areas of life including family, community and society. The GIRFEC principles also set out the importance of providing support for children, young people and families when they need it, until things get better, to help them to reach their full potential. This is achieved by everyone working together in local areas and across Scotland to improve outcomes for children, young people and their families.

Further detail on the policy and the SHANARRI indicators is set out in Section 3.2.3.

Self-Directed Support: Improvement Plan 2023 to 2027 (2023)

This plan recognises the need for a whole-system approach to improving the delivery of SDS.(120) The plan identifies four main outcome areas where improvements need to be made. These are:

- supported person and carer's choice over their support
- enhanced worker skills, practice and autonomy
- systems and culture, where success means national and local SDS system and planning design is more person-centred and person-led
- leaders understand and help staff realise SDS principles and values.

3.2.5 Regulation, monitoring and inspection of assessment of need

In partnership with Health Improvement Scotland, Education Scotland and His Majesty's Inspectorate of Constabulary (HMICS), the Care Inspectorate carries out joint inspections of local authority services for children and young people in need of care and protection. These inspections focus on children at risk of harm and looked after children. There is not a rolling programme of inspection or monitoring of assessment of need for children with disabilities.

The Care Inspectorate has a number of quality frameworks to support services to self-evaluate their own performance. They are also used by inspectors to provide independent assurance about the quality of care and support. By setting out what they expect to see in high-quality care and support provision, the frameworks also help support improvement. The frameworks reflect Scotland's *Health and Social Care Standards*, which are rights-based, person-led and outcome-focused and are relevant for care delivery, planning, commissioning, and assessment. They are also aligned to the appropriate legislation and relevant national good practice.(111) While there are no quality frameworks specific to assessment of need for children with disabilities, local authorities may adapt other quality frameworks for use in self-assessment.

At the time of writing, the Care Inspectorate is undertaking a thematic review of how well social work is meeting the needs of children and young people with disabilities across four local authorities (see Section 3.2.6).

3.2.6 Findings from reviews

In 2019, the Care Inspectorate published a *Thematic Review of Self-Directed Support in Scotland: Transforming Lives* (2019), which was carried out jointly with Healthcare Improvement Scotland.(121) The review considered the delivery of self-directed support (SDS) in six community planning partnerships[‡‡] across Scotland to evaluate how well they had embedded the principles and values of this approach to deliver better outcomes for supported people. Inspections explored the extent to which the partnerships had ensured that:

- people were supported to identify and achieve personal outcomes
- people experienced choice and control
- people felt positive about their engagement with professionals and services
- there was information, choice and flexibility for people when accessing services
- staff were enabled and empowered to implement SDS
- leaders had embedded the principles and values of SDS in practice.

The review found that most partnerships had yet to fully implement SDS, meaning that its true potential was not being realised. The review found that good conversations were often taking place between supported people and staff to inform assessments and support plans. However, discussions and decisions about options, choice and control were not routinely documented in case records. Among the review's recommendations were that partnerships support staff to more accurately record good conversations around choice and control. It also recommended that

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[‡‡] A Community Planning Partnership refers to all public services that come together to take part in community planning. There are 32 CPPs across Scotland, one for each council area.

partnerships further develop and implement systems and processes for assessment, budget-allocation and support planning that are designed to support a personal outcome approach, rather than follow a deficit-based model.

The Care Inspectorate's *Disabled Children and Young People: Thematic Review 2023-24* will provide a national overview of social work's contribution to how well the needs of children and young people with disabilities are assessed, planned for and met.(122) The review is structured under the two following statements:

- Children and young people are actively heard, informed, and meaningfully involved in decisions about their lives.
- Children's and young people's wellbeing has been promoted through high quality child-centred planning and bespoke support.

It is expected that the review will be published in August 2024. Preliminary findings indicate variation in how assessments are carried out around the country, though most adhere to the Getting It Right For Every Child (GIRFEC) approach.[§§]

3.2.7 Key findings

In Scotland, legislation outlines that the responsibility for assessment of need lies with local authorities and they have a duty to provide services to meet identified needs. Under the Children (Scotland) Act 1995, local authorities have a duty to assess people aged under 18 with disabilities. Once assessment is completed, a social worker should draw up a 'child in need care plan'. While local authorities determine their own method of assessment, the Children and Young People Act 2014 stipulates that the local authority must assess the wellbeing of a child or young person with reference to the use of the SHANARRI indicators. Local authorities generally use SHANARRI as part of an integrated assessment under the Getting It Right For Every Child (GIRFEC) approach. This is a holistic assessment which encompasses three domains:

- the child's developmental needs
- parents' or caregivers' capacity to respond to those needs
- wider family and environmental factors.

GIRFEC guidance for practitioners and managers provides a framework to structure and analyse information consistently to take account of the strengths and challenges faced by a child or young person, alongside their needs, and to consider the support

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[§§] This information was provided by subject matter experts from Care Inspectorate Scotland, interviewed on 19 March 2024 to inform this research report.

that may be required. It also enables full participation of children, young people and their families in joint decisions to plan and deliver that support.

As such, it is of interest to Ireland that the GIRFEC model provides a consistent assessment framework for use across the country, though local authorities have discretion in their assessment processes. GIRFEC focuses on having services that follow the child, and so encourages multi-agency working. It is also of note that assessments are not looked at in isolation, but as part of a continuum of care and support planning and service provision, and efforts are made to ensure that a single lead practitioner coordinates the entire process. Scotland differs from Ireland in stipulating that carers also have a right to an assessment of their needs, and this emphasises the need to provide support for the family or caregivers around the child or young person with disabilities.

In a separate process, education authorities carry out assessments of special educational needs in order to determine whether a formal record of needs should be opened.

There is no rolling programme of inspection or monitoring of assessment of need for children with disabilities, though at the time of writing, the Care Inspectorate is conducting a thematic review of social work services for children and young people with disabilities. This review looks at how needs are assessed, planned for and met, and early results have indicated some variability across the country which might point to challenges in implementing standardised practice.

3.3 Wales

This section describes the organisation and delivery of assessment of need services in Wales. This section is set out under the following headings:

- overview of assessment of need
- the model of service
- relevant legislation
- standards, guidance, frameworks, strategies and policies
- regulation, monitoring and inspection of assessment of need
- findings from reviews
- key findings.

3.3.1 Overview of assessment of need

In Wales, children with disabilities have a statutory entitlement to an assessment of their needs for care and support under Section 21(7) of the Social Services and Well-being (Wales) Act 2014.(123) The Care and Support (Assessment) (Wales) Regulations 2015 and the Care and Support (Care Planning) (Wales) Regulations 2015 set out how assessments and care planning should be conducted.(124,125) In 2022, the population of Wales was estimated to be 3.1 million people; people with a disability accounted for 26% of the population.(60,126)

The Department of Health and Social Services has overall authority for health and social care services in Wales. Local authorities are responsible for carrying out assessments, with services delivered by local authorities and National Health Service (NHS) Wales. Assessments are required to be holistic and child-centred in nature. Following an assessment, services are provided through the local authority, by means of direct payments or by local health boards where required.

While there are no standards specific to assessment of need, there are high-level health and care quality standards that set out what people in Wales can expect when accessing health services, as well as professional standards for the care and support workforce.(127,128,129) Inspection and monitoring of how local authorities carry out their social services functions is delivered by Care Inspectorate Wales, with the aid of Health Inspectorate Wales, where needed.

A review carried out by Care Inspectorate Wales in 2021 of how well local authorities provided early help, care and support and transition for children with disabilities, found that assessment and care and support planning must be strengthened.(130)

3.3.2 The model of service

In Wales, responsibility for the delivery and organisation of assessment of need lies with local authorities. This section sets out the model of service under the following headings:

- structure and governance of assessment of need
- scope of assessment of need
- assessment of need process
- appeals process.

Structure and governance of assessment of need

Assessment of need falls within the remit of the Department of Health and Social Services. There are 22 local authorities in Wales, these are county and county borough councils – also known as ‘principal councils’, which deliver social services. These local authorities have duties under the Social Services and Well-being (Wales) Act 2014 to assess and meet the needs of children for care and support.

Scope of assessment of need

Children with disabilities have a right to an assessment under Section 21(7) of the Social Services and Well-being (Wales) Act 2014. During this assessment for care and support, assigned staff work with an individual, carer and family, and other relevant individuals to understand their needs, capacity, resources and the outcomes they need to achieve. The next step is to identify how they can best be supported to achieve them, and what contribution the individual and their family can make to achieving those outcomes. Principles underpinning assessment include partnership, focusing on a person’s needs and strengths, and supporting people to contribute to their own personal outcomes.

There is a separate statutory assessment of special educational needs (SEN) under the Education Act 1996, which may result in a Statement of SEN.(131) At the time of writing, a new system of support for children with additional learning needs (ALN), called the ALN Framework, is being phased in.(132)

Assessment of need process

The assessment process may start when a person makes a request to the Information, Advice and Assistance (IAA) service. This is a local authority service providing people in its catchment area with information and advice in relation to care and support. An assessment can be undertaken by a single practitioner, where that practitioner would not need additional specialist advice or assessments to determine eligibility. All practitioners undertaking assessments must be qualified. This may be a registered social work or social care practitioner holding a qualification at level five or above in the national framework for qualifications, or a person holding a social care qualification at level four or above, which includes knowledge and skills for undertaking person-centred assessment. A person with a qualification at level four must work under the supervision of a registered social work or social care practitioner.(133) The practitioner undertakes an assessment that is proportionate to the needs and circumstances of the child. An assessment must be completed within 42 working days of referral.(128)

The Social Services and Well-being (Wales) Act 2014, Part 3 Code of Practice sets out several principles underpinning the approach to assessing children and their families.(128) Among the principles are that assessment must be holistic, child centred and rooted in child development, and assessors must work with children and their families and build on their strengths. Further, the code sets out that an inter-agency approach to assessment and service provision must be taken, and the assessment process must be carried out alongside the delivery of services. The principles also present assessment as a continuing process, not a single event.

To support the holistic assessment process for children, practitioners gather evidence as informed by three domains of the assessment of children. These domains encompass a child’s developmental needs, the parents’ or caregivers’ capacities to respond appropriately to these needs, and wider family and environmental factors impacting on these needs.(128) These areas of enquiry must be analysed against five inter-related elements of assessment to inform the development of the care and support plan. Statutory assessment and eligibility criteria require a local authority to:

1. assess and have regard to the person’s circumstances
2. have regard to their personal outcomes
3. assess and have regard to any barriers to achieving those outcomes
4. assess and have regard to any risks to the person or to other persons if those
5. outcomes are not achieved
6. assess and have regard to the person’s strengths and capabilities.(134)

An assessment may conclude that, immediate needs having been met, a more comprehensive assessment is required. This can be undertaken by a single practitioner or one or more professional assessors and may involve several stages or discussions. The statutory guidance states that the need for a more specialist assessment to be undertaken must not prevent or delay appropriate services being provided.(128) As such, the local authority must ensure that any delay in completing the specialist assessment is minimised, so that a care and support plan can be progressed quickly. The local authority should consider whether it is appropriate to put interim support in place. In all cases, a designated lead practitioner must be named and lead the assessment process. The process of assessment must recognise the reality of fluctuating needs and capacity and be responsive to changing circumstances. The person, and any others involved, should be kept informed of the progress of the assessment and expected timescales for completion of the assessment process.

Assessments must, at a minimum, record the assessment in line with the national assessment and eligibility tool.(135) This tool is a framework for assessment and eligibility, which comprises:

1. the national minimum core data set
2. an analysis structured around the five elements of the assessment, including setting out the outcomes which have been identified
3. the actions to be taken by the local authority and other persons to help the person achieve those outcomes
4. a statement of how the practitioner assesses the identified action will contribute to the achievement of the personal outcome or otherwise meet needs identified by the assessment.

The obligation to complete the core dataset in its entirety is only required when an individual’s needs are deemed to be eligible for a care and support plan.

If the assessment concludes that a care and support plan is needed, it must be produced ‘without delay’, though there are no statutory timeframes for completion. The support plan must include identified outcomes; actions to be taken by the local authority and other persons; the needs that will be met through the delivery of care and support; how progress towards achieving those outcomes will be monitored and measured; and the date of the next review of the care plan.(136)

The care and support plan, and the services offered to meet these care and support needs, must be reviewed every six months. The statutory code of practice on meeting needs states that there must be a named person to coordinate the preparation, review, delivery and revision of the plan, in many cases this will be the same practitioner as the assessment coordinator.(129) The person has the right to request a re-assessment of their needs at any time. A formal process for making this request must be developed, published and clearly communicated by the local authority.

The 2014 Act sets out eligibility criteria to assist local authorities in determining who to provide care and support to following assessment, and whether charges should apply.(123) Where a child has a disability, the presumption is that they have a need for care and support in addition to or instead of that provided by their family. To determine eligibility, the following is considered:

1. ability to carry out self-care
2. ability to communicate
3. protection from abuse or neglect
4. involvement in work education, learning or leisure activities
5. maintenance or development of family or other significant personal relationships
6. development and maintenance of social relationships and involvement in the community
7. achieving developmental goals.

Appeals process

Parents or guardians can lodge a formal complaint with the local authority if they are dissatisfied with the result of the assessment or the subsequent care and support plan. Under the Social Services Complaints Procedure (Wales) Regulations 2014, there is a two stage process to deal with complaints about local authority social services:

- the local resolution stage – face-to-face or telephone discussion with a view to resolution
- the formal investigation stage (at this stage an independent investigator is appointed).(137)

Each local authority must designate a senior officer to be responsible for oversight of the complaints procedure and must appoint a complaints officer to manage the procedures. A complaint may be made up to 12 months after the date on which the subject of the complaint occurred.

If a resolution is not reached, the complaint may proceed to a formal investigation. If the matter is not resolved, the complainant can complain to the Public Services Ombudsman for Wales.(138) Details of timeframes and escalation of complaints are set out in regulations.

3.3.3 Relevant legislation

The central piece of legislation for assessment of need for children with disabilities is the Social Services and Well-being (Wales) Act 2014 and associated regulations:

- The Social Services and Well-being (Wales) Act 2014
- The Care and Support (Assessment) (Wales) Regulations 2015
- The Care and Support (Care Planning) (Wales) Regulations 2015
- The Care and Support (Eligibility) (Wales) Regulations 2015.(134)

The Social Services and Well-being (Wales) Act 2014

This Act provides the legal framework for improving the wellbeing of people who need care and support, as well as carers who need support, and for transforming social services in Wales. The fundamental principles of the Act are:

- the Act supports people who have care and support needs to achieve wellbeing
- people are at the heart of the new system by giving them an equal say in the support they receive
- partnership and co-operation drives service delivery
- services will promote the prevention of escalating need and the right help is available at the right time.

The Act sets out to ensure that assessment and care planning is carried out in the best way to meet an individual's needs. The focus is on what matters to the person and how they can use their own strengths and resources to do those things. Under the Act, the expectation is that assessment is a partnership between the person and the professional.

The Care and Support (Assessment) (Wales) Regulations 2015

The regulations specify that there must be a named individual whose function is to coordinate the assessment, and that those carrying out assessments must have the necessary training and competencies. In carrying out assessments, local authorities must:

- assess and have regard to the person's circumstances
- have regard to the personal outcomes
- assess and have regard to any barriers to achieving those outcomes

- assess and have regard to any risks to the person or to other persons if those outcomes are not achieved
- assess and have regard to the person's strengths and capabilities.

An assessment must be reviewed if there has been a significant change in the person's circumstances or in their personal outcomes.

The Care and Support (Care Planning) (Wales) Regulations 2015

These regulations ensure that those preparing a care and support plan have the relevant skills and training to do so (the related code of practice specifies the level of social work professional qualifications at Level 5 or above, or Level 4 or above under supervision).(129) It also sets out that where needs are being met by direct payments, the plan must detail the eligible needs to be met by the payments, and the amount and frequency of the payments. The regulations stipulate what must be included in care and support plans and arrangements for review (for more detail see Section 3.3.2).

The Care and Support (Eligibility) (Wales) Regulations 2015

These regulations set out the test which a local authority must apply to determine whether or not an individual with needs identified in an assessment is entitled to have those needs met by a local authority. In the case of a child, the eligibility criteria are met if the need arises from physical or mental ill-health or disability; further detail is given in Section 3.3.4.

3.3.4 Standards, guidance, frameworks, strategies and policies

While there are no standards specific to assessment of need, there are high-level health and care quality standards that set out what people in Wales can expect when accessing health services, and professional standards for the care and support workforce. There is statutory guidance on assessment of needs and the preparation of care and support plans, related to the Social Services and Well-being (Wales) Act 2014. This section provides further detail on standards, guidance, strategies and policies relating to assessment of need.

Standards

Local authorities undertaking assessments of need work in line with the Social Services and Well-being Act 2014 and the associated statutory codes of practice, which are set out in more detail in Section 3.3.4. The Care Inspectorate monitors the performance of local authority social services with regard to the four principles underpinning the 2014 Act (see Section 3.3.3).

The Health and Care Quality Standards (2023) are high-level standards used by Healthcare Inspectorate Wales (HIW) when undertaking reviews and investigations.(127) They comprise six domains of quality: safe, timely, effective, efficient, equitable and person centred, supported by six quality enablers (leadership, workforce, culture, information, learning, improvement and research, and whole systems approach).

Social Care Wales is the regulator of the social care profession and sets standards for the care and support workforce. It develops codes of practice for workers, codes for employers, practice guidance for registered workers and information on what people using care and support should expect from social care workers.

Implementation of standards

Social Care Wales has a training module for social workers on *Assessing and Meeting the Needs of Individuals* (2017).(139) The module summarises and explains the regulations and codes of practice that underpin the Social Services and Well-being (Wales) Act 2014. It is designed to help those whose roles are most affected by the 2014 Act to understand and implement it.

Guidance

There are two statutory guidance documents on assessing and meeting the needs of individuals, in accordance with the Social Services and Well-being (Wales) Act 2014:

- Social Services and Well-being (Wales) Act 2014, Part 3: Code of Practice (assessing the needs of individuals)
- Social Services and Well-being (Wales) Act 2014, Part 4: Code of Practice (Meeting Needs).(129)

Implementation of these codes of practice by local authorities is monitored by the Care Inspectorate; more detail is given in Section 3.3.5.

Social Services and Well-being (Wales) Act 2014, Part 3 Code of Practice (assessing the needs of individuals) (2015)

The code of practice on assessing the needs of individuals outlines a model of assessment and care planning that requires the assessment process to start with the person themselves and understand their strengths and capabilities and what matters to them, and how their family, friends and local community play a part in their life to help them reach their personal outcomes. Where the assessment is of the care and support needs of a child, this includes observation of the child and communicating with the child in an age and capacity-appropriate manner. The assessment must address the central or most important aspects of the needs of a child and the capacity of his or her parents or caregivers to respond appropriately to these needs within the wider family and community context.

A designated lead practitioner must be named and lead the assessment process. Where a more comprehensive assessment is required, an integrated assessment may contain one or more professional assessments which are designed to suit the specific assessment task of that professional discipline. Where it is required to meet the principles of the code of practice, the local authority must involve someone with specialist skills, knowledge or expertise in the assessment process. The presumption is in favour of the expert opinion in cases where the expert and generalist practitioner do not agree. The code sets out that the need for a more specialist assessment to be undertaken must not prevent or delay appropriate services being provided.

Social Services and Well-being (Wales) Act 2014, Part 4: Code of Practice (Meeting Needs) (2015)

This code of practice sets out national eligibility criteria, the care planning process (including direct payments) and the operation of direct payments. It is a principle of the Act that a local authority should respond in a person-centred, co-productive way to each individual's particular circumstances. Individuals and their families must be able to participate fully in the process of determining and meeting their identified care and support needs, through a process that is accessible to them. In terms of eligibility, there is a presumption that a child with a disability has a need for care and support in addition to that provided by their family. The approach to assessment of need and determining eligibility must be one that focuses on people's strengths and capabilities, as well as on their needs and the barriers they face, to achieve their personal outcomes.

Strategies and policies

Action on Disability: The Right to Independent Living Framework and Action Plan (2019) was created following extensive engagement with people with disabilities and the organisations who represent them.(140) It sets out the principles, legal context and commitments which underpin all of the Welsh Government's work with, and for, people with disabilities. The framework's main aims are to:

- improve access to help, advice and services for people with disabilities
- promote equality of opportunity
- enable people with disabilities to more easily and readily access resources and mainstream services

- focus on the key issues identified by people with disabilities and set out what the Welsh Government can do to remove the barriers they face.

There is no specific reference in the framework to assessment of need as a process.

3.3.5 Regulation, monitoring and inspection of assessment of need

Care Inspectorate Wales is the independent regulator of social care and childcare in Wales. It reviews the performance of local authorities in delivery of social services functions through a combination of inspection and performance evaluation activity. Healthcare Inspectorate Wales (HIW) is the independent inspectorate and regulator of healthcare, and provides assistance to the Care Inspectorate in its evaluation of local authority social services where needed.

Inspections of local authority social services include reviews of assessments of needs, and care and support planning. These inspections are undertaken against the Social Services and Well-being Act 2014 under the principles of People – voice and control; Prevention; Wellbeing; and Partnerships. Inspectors also review services that children and young people are receiving; as such, they review the entire journey from assessment to the service provided.

Under the Well-being of Future Generations (Wales) Act 2015, Welsh Ministers must report annually on the progress made towards the achievement of wellbeing.(141) *The National Outcomes Framework 2022: A Report on the Well-being of People Who Receive Care and Support and Unpaid Carers Who Receive Support* (2023) contains indicators on securing rights and entitlements, including the percentage of people who felt involved in decisions about their care and support, and the percentage of people whose care and support has helped them have a better quality of life.(142) There are no indicators specific to assessment of need.

3.3.6 Findings from reviews

A key review related to assessment of need is *'Let me flourish' - National Review of Early Help, Care and Support and Transition for Disabled Children in Wales* (2021). This review by the Care Inspectorate Wales looks at how well local authorities, working with their partners, provide early help, care and support and transition for children with disabilities.(130) A key finding was that assessment and care and support planning must be strengthened. The review found that the quality of assessments and care and support plans varied across local authorities in Wales, as did the quality assurance processes in place to monitor them. The review found that the best examples of practice ensured the voice and choice of the child with a disability and family members were prominent within assessments and care and support plans. There were clearly-defined strengths, risks and barriers; plans were outcome focused and clear contingency planning was in place. In other examples, the review found improvements were needed, as the voice and choice of the child was not prominent, and strengths, risks and outcomes were not clearly identified.

3.3.7 Key findings

Children with disabilities have a right to an assessment under Section 21(7) of the Social Services and Well-being (Wales) Act 2014, and the local authority has a duty to provide services necessary to meet identified needs. Principles underpinning assessment include partnership, focusing on a person’s needs and strengths, and supporting people to contribute to their own personal outcomes. There are clear regulations and statutory guidance on assessment, and care and support planning. These set out underpinning principles, elements of assessment, statutory timelines, eligibility criteria, and how assessments should be recorded. Support may be provided through provision of services or direct payments. Care and support plans and services must be reviewed every six months.

Care Inspectorate Wales reviews the performance of local authorities in delivery of social services functions and does so through a combination of inspection and performance evaluation activity. Healthcare Inspectorate Wales (HIW) provides assistance to the Care Inspectorate in its evaluation of local authority social services where needed. A 2021 Care Inspectorate review of how well local authorities provided early help, care and support and transition for children with disabilities found that assessment and care and support planning must be strengthened. The review identified variances in the quality of assessment and care and support planning across the country, and variance in quality assurance processes.

A key learning from the system in Wales is the holistic nature of the statutory assessment, which covers three domains (developmental needs, caregiver capacity and the wider environment), and the statutory duty on local authorities to provides services for children in need. The statutory basis of the code of practice serves to strengthen the requirement that all assessments be holistic, strengths-based and involve children and their families. Also of note is the inter-agency approach to assessment and service provision, and that assessment must be carried out alongside delivery of services. Furthermore, the code of practice stipulates that assessment must a continuing process, not a single event.

Assessment of special educational needs is a separate process. There is a statutory assessment of special educational needs (SEN) under the Education Act 1996 which may result in a Statement of SEN.

As in other UK jurisdictions, carers also have a right to an assessment of their needs. Another key learning for Ireland is that, where possible, one professional stays with the child or young person from assessment through to care and support planning and service provision. This provides a consistent point of contact for families.

Similarly, assessment of need is not treated in isolation in the inspection process; regular inspection of local authority social care services includes the entirety of assessment, care planning and service provision.

3.4 Northern Ireland

This section describes the organisation and delivery of assessment of need services in Northern Ireland. This section is set out under the following headings:

- overview of assessment of need
- the model of service
- relevant legislation
- standards, guidance, frameworks, strategies and policies
- regulation, monitoring and inspection of assessment of need
- findings from reviews
- key findings.

3.4.1 Overview of assessment of need

In Northern Ireland, children with disabilities have a statutory entitlement to an assessment of need under the Children (Northern Ireland) Order 1995.(143) In 2021, the population of Northern Ireland was estimated to be 1.9 million people; people with disabilities accounted for 22% of the population.(60,144)

The Department of Health has overall authority for health and social care services. There are five Health and Social Care (HSC) Trusts which are responsible for carrying out assessment of need and there is some variation in how statutory children's social care services are structured across Northern Ireland.(145)

Assessments are carried out by children's social care services in a HSC Trust. For a child in need assessment, Northern Ireland uses a holistic inter-agency assessment model called UNOCINI (Understanding the Needs of Children in Northern Ireland). The 2011 UNOCINI guidance is under review at the time of writing.(146) Following assessment and preparation of a care plan, services can be provided directly by the HSC Trust or through a system of direct payments. If a child is considered to be a 'child in need', services are offered to assist the child's parents or carers to meet that identified need. An unpaid carer also has an entitlement to a carer's assessment.

There are no standards specific to assessment of need, however, there are a number of health and social care standards and guidance relevant to assessment of need, including *Understanding the Needs of Children in Northern Ireland (UNOCINI) Guidance* (2011). The Regulation and Quality Improvement Authority (RQIA) is the independent body responsible for monitoring and inspecting the availability and quality of health and social care services in Northern Ireland, and encouraging improvements in the quality of those services.(147) RQIA reviews the performance of HSC Trusts, but there is no specific programme for inspection or monitoring of assessment of need for children with disabilities.

The Report of the Independent Review of Northern Ireland's Children's Social Care Services (2023) noted that in March 2021, over 5,000 children were waiting for an assessment related to autism; waiting lists for child and adolescent mental health services (CAMHS) continue to grow, although they have recently stabilised, and there is significant variance in waiting lists between HSC Trusts.(145) At the time of writing, there are significant challenges around workforce recruitment and retention, with the number of vacancies actively being recruited within the 5 trusts running at 5,089.(148)

3.4.2 The model of service

In Northern Ireland, responsibility for the delivery and organisation of assessment of need lies with Health and Social Care (HSC) Trusts. This section sets out the model of service under the following headings:

- structure and governance of assessment of need
- scope of assessment of need
- assessment of need process
- appeals process.

Structure and governance of assessment of need

The Department of Health has overall authority for health and social care services. There are five HSC Trusts which are responsible for carrying out assessment of need. These may be carried out by a Children's Disability Team or a 'Child in Need' team. There is variation in how statutory children's social care services are structured across Northern Ireland. In 2008, a region-wide arrangement was introduced for the provision of statutory children's social care within the HSC Trusts. It had a structure of Gateway teams, Family Intervention teams, Looked After Children teams, and Leaving Care teams, with separate teams for children with a disability, fostering and adoption, for court welfare services for private family law proceedings, and for the registration of early years services such as child minders and day care. Research shows that while some Trusts work according to this model, others have merged teams, and there are differences in what responsibilities are held within similar teams across Trusts.(145) For example, there are differences in whether or not Children's Disability Teams undertake child protection investigations.

Scope of assessment of need

Children with disabilities have a right to an assessment under Article 18 of the Children (NI) Order 1995.(143) A child is in need if:

- he or she needs the support of local authority services to achieve or maintain a reasonable standard of development or health
- he or she needs the support of local authority services to prevent the impairment of or further harm to their development or health
- he or she has a disability.

A Statutory Assessment and Review Service carries out assessments of special educational needs (SEN) and provides a Statement of SEN where required.

Assessment of need process

HSC Trusts can use slightly different methods of assessment, but generally follow the Understanding the Needs of Children in Northern Ireland (UNOCINI) Assessment Framework. Eligibility criteria are applied to provide services to those most in need. Staff undertaking the assessments come from a range of health and social care backgrounds, with the majority having a social work qualification, others coming from nursing, and some with no health or social care qualifications. Following an assessment, HSC Trusts may provide services or provide direct payments to parents or carers so that they can arrange their own care and services.

When a child is referred, children's social care services undertake an initial assessment to determine if that child is a 'child in need' as defined by the Children Order. Assessments are generally conducted under the UNOCINI Assessment Framework.(146) The UNOCINI framework is developed around a set of core principles:

1. Assessment is undertaken in partnership with the child and their family.
2. Assessments are balanced, incorporating all factors impacting upon the child and their family's lives, and should build on strengths; be child centred and rooted in child development, be knowledge based and show evidence, and incorporate an assessment of the child's need for protection from themselves or others.
3. Professional interventions are based on a clear assessment of need that informs decision making and action.
4. Intervention at an earlier stage is preferable.

5. Assessment is a continuous process, not a ‘one off’, and
6. Value the contribution that different professionals and agencies can make to understand and meet needs.

There are four phases in the framework:

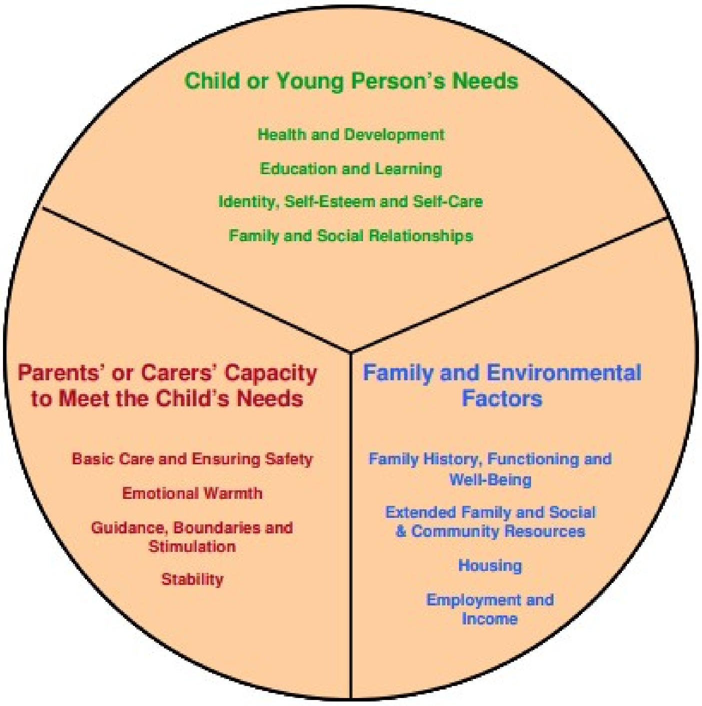
1. agency appraisal and preliminary assessment
2. referral
3. initial assessment
4. pathway assessment.

A preliminary assessment is a desktop exercise using the UNOCINI preliminary assessment template to analyse information and help consider what the appropriate response to a child and family’s needs might be. There is no engagement with the child or family at this stage. If a referral is made to children’s social services, then an initial assessment is completed. This initial assessment is not an in-depth exploration, but rather an overview of current circumstances. If this indicates that children’s social services need to be involved, then a more detailed and comprehensive UNOCINI Family Support Pathway Assessment is completed. This is tailored to the type of service most likely to meet the child or young person’s needs.

This assessment is an in-depth assessment of a child and family’s circumstances. It is likely to be developed over several weeks, involving a series of meetings with children and their families. The assessment can be holistic, or focused on a particular domain such as the child’s needs, the parent’s or caregiver’s capacity to meet those needs, and or family and environmental factors. Following a family support pathway assessment, the guidance states that an initial family support plan is to be completed within 20 working days from receipt of referral. The first review of the family support plan is to be completed within three months of the initial plan. Subsequent review plans are to be completed at six-monthly intervals, or at more frequent intervals if needed and or requested. Following preparation of a care plan, services can be provided directly by the HSC Trust or by means of direct payments.

As noted, the UNOCINI framework is divided between three areas: the child’s needs, parent’s capacity to meet these needs, and family and environmental factors which impact on the child or young person. These three areas are then divided into 12 domains, as illustrated in Figure 4, below.

Figure 3. The areas and domains of the UNOCINI assessment framework



Source: Department of Health (NI). *Understanding the Needs of Children in Northern Ireland (UNOCINI) Guidance*. 2011.(146)

The four common themes that must be considered and appraised through the assessment framework are the needs and strengths of the child and their family, the existing and potential risks to the child and their family, and the resilience and protective factors within and around the child and their family. The model also proposes four levels of need:

1. Level 1: base population
2. Level 2: children with additional needs – vulnerable children who may be at risk of social exclusion
3. Level 3: children in need – children with complex needs that may be chronic and enduring
4. Level 4: children with complex and or acute needs – children in need of rehabilitation; children with critical and or high risk needs; children in need of safeguarding; children with complex and enduring need.

Specialist assessments apply across children who are at Level 2 to Level 4. Children at Level 2 receive a UNOCINI preliminary assessment; children at Level 3 receive a UNOCINI initial assessment, which may lead to a UNOCINI pathway assessment

(Level 4). In terms of education, for children at Level 3, there is consideration of referral for statutory assessment and a statement of special education needs.

Appeals process

Parents or guardians can use the relevant HSC Trust complaints procedure if they are unhappy with the way the assessment has been conducted or the decisions made. There are eight standards for complaints handling, which are set out in the *Guidance in Relation to the Health and Social Care Complaints Procedure* (2019).(149) There is no formal appeals process in place for assessment of needs, however the Department of Health funds advocacy organisations, and parents can be directed to these, if required. Complaints which are not resolved at an early stage may go to judicial review or the Northern Ireland Public Services Ombudsman.

3.4.3 Relevant legislation

The central piece of legislation for assessment of need for children with disabilities is the Children (Northern Ireland) Order 1995. The Chronically Sick and Disabled Persons (Northern Ireland) Act 1978 sets out the responsibilities of Health and Social Care (HSC) Trusts in providing certain services.(150) This section covers the following legislation in relation to assessment of need:

- The Children (Northern Ireland) Order 1995
- Children's Services Co-operation Act (Northern Ireland) 2015
- The Chronically Sick and Disabled Persons (Northern Ireland) Act 1978

The Children (Northern Ireland) Order 1995

The Children (Northern Ireland) Order 1995 (the Children Order) is the principal statute governing the care, upbringing and protection of children in Northern Ireland.(143) It applies to all those who work with and care for children, whether parents, paid carers or volunteers. It covers the full range of safeguarding activity, including the promotion of a child’s welfare, assessment of a child’s needs, provision of support for children and families, protection of children, and powers to assume or secure parental responsibility for children when required. The legislation is broadly in line with the Children Act 1989, which covers England and Wales.

Children with disabilities have a right to an assessment under Article 18 of the Order, which outlines the duty of the authority to provide personal social services ‘to safeguard and promote the welfare of children within its area who are in need’. The related legislation in England (Children Act 1989) was interpreted by the courts to include a right to an assessment of need. To promote a child’s welfare, the HSC Trust then has a duty to provide any services necessary to meet their needs. Article

17 of the Children (Northern Ireland) Order 1995 includes children with disabilities in its definition of children in need.

Children's Services Co-operation Act (Northern Ireland) 2015

This Act requires public authorities to co-operate in contributing to the wellbeing of children and young people, in the areas of:

- physical and mental health
- enjoyment of play and leisure
- learning and achievement
- living conditions, rights, and economic wellbeing.(151)

The Act places a requirement on individuals and organisations providing children's services to co-operate with each other to devise and implement cross-cutting strategies. The Act is key to ensuring improved outcomes for children by supporting, enhancing and encouraging co-operation, so that services are integrated from the point of view of the child or young person.

The Chronically Sick and Disabled Persons (Northern Ireland) Act 1978

This Act sets out the areas in which a HSC Trust must provide an identified service. It gives rights in relation to practical assistance in the home, provision of meals, facilitating holidays, and participating in services.

3.4.4 Standards, guidance, frameworks, strategies and policies

There are a number of health and social care standards and guidance relevant to assessment of need. The key guidance for conduct of assessments is *Understanding the Needs of Children in Northern Ireland (UNOCINI) Guidance*, which at the time of writing is being reviewed and updated. While, the *Children and Young People's Strategy 2020-2030* provides an overarching framework for supporting the wellbeing of children and young people in Northern Ireland, it does not explicitly mention assessment of need.(152) Significantly, the *Autism Strategy 2023-2028* prioritises intervention and support based upon presenting need, rather than the practice of requiring assessment and diagnosis before support is given.(153) This section provides further detail on standards, guidance, strategies and policies relating to assessment of need.

Standards

The Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003 applied a statutory duty of quality on Health and

Social Care (HSC) Trusts.(154) This means that each organisation, large or small, has a legal responsibility to ensure that the care it provides must meet a required standard. Service frameworks set out standards for health and social care to help people understand the standard of care they can expect to receive. They are also to be used by health and social care organisations in planning and delivering services. The standards and service frameworks covered in this section are:

- Quality Standards for Health and Social Care (2006)
- Service Framework for Children and Young People's Health and Wellbeing (2017)
- Service Framework for Learning Disability (2015).

While these service frameworks outline particular standards to be met, in practice those undertaking assessment of need for children with disabilities in HSC Trusts refer predominantly to the UNOCINI framework. At the time of writing, there is no system of inspection or monitoring of assessment of need with reference to these standards and service frameworks, but they are significant in indicating desired outcomes.

Quality Standards for Health and Social Care (2006)

This document sets out high-level quality standards for health and social care services across Northern Ireland. The standards are described as 'essential' and set a minimum standard to ensure safe and effective practice.(155) Importantly, in relation to service delivery, the quality standards state that a HSC organisation 'incorporates the rights, views and choice of the individual service user into the assessment, planning, delivery and review of his or her treatment and care…' and 'promotes multi-disciplinary team work and integrated assessment processes'.

Service Framework for Children and Young People's Health and Wellbeing (2017)

Service frameworks aim to set out clear standards of health and social care that are evidence based and measurable. The *Service Framework for Children and Young People* sets standards that relate to improving birth outcomes, child development across the life course, acute and long-term conditions, positive mental health and emotional wellbeing, childhood disability, and children and young people in special circumstances.(156)

Standard 12 states that 'All children, young people and their carers should have access to a range of early intervention services in response to their identified need.' Key performance indicators include that each HSC Trust area should have a range of early intervention programmes in place for pre-pregnancy, antenatal, post-natal, early years, primary school, and post-primary school, and sets out that levels of need are recorded on the Child Health System.

Standard 19 states that 'Children with disability and their families should be fully supported to participate in valued childhood experiences and to have access to the same opportunities, life experiences and services as other children.' Key performance indicators for Standard 19 are the number of care plans in place for children with disabilities, that all children with disabilities are accessing preschool services and support, that all children in preschool years where carers express concern about development are seen within six weeks, and the numbers of carers assessments where there is a child with a disability in a family.

Service Framework for Learning Disability (2015)

This framework aims to improve the health and wellbeing of people with a learning disability, their carers and families, by promoting social inclusion, reducing inequalities in health and social wellbeing and improving the quality of health and social care services.(157)

Standard 10 states that 'From the point at which concerns are raised that a child or young person may have a learning disability, there is an action plan in place to determine the nature and impact of the learning disability.' The key performance indicator is the percentage of parents who express satisfaction with the assessment process and how the outcomes were conveyed.

Standard 11 states that 'Children and young people should receive child-centred and co-ordinated services through assessment to ongoing care and support from the point at which a determination has been made that they have a learning disability.' Key performance indicators include the percentage of children and young people with a learning disability and carers who have been offered an annual assessment, either under the Family Health Needs Assessment or UNOCINI Assessments, and the percentage of these who have an agreed care plan detailing a pathway to receiving appropriate care and support.

Standard 12 states that 'HSC services should respond to the needs of children and young people who have a learning disability and complex physical health needs in a manner that is personalised, developmentally appropriate and which supports access to appropriate care.' Key performance indicators include the percentage who have a key worker with co-ordinating responsibility, the percentage who have effective transition arrangements between hospital and community, and the percentage who have received a multi-professional assessment as per the regional integrated care pathway.

Standard 14 states that 'Young people with a learning disability should have a transition plan in place before their 15th birthday and arrangements made for their transition to adulthood by their 18th birthday.' Key performance indicators are the percentage who express satisfaction that their transition plan has been implemented within two years of leaving school, and evidence of transfer to Direct Enhanced Services (a specialised service provided by GPs for adults with severe learning disability), where appropriate, for health checks for children who are transitioning to adult services.

Guidance

As noted, at the time of writing, the Department of Health is reviewing the UNOCINI guidance for assessment of need.(146) The guidance is aimed at practitioners who provide services to children, young people and their families, whether they work in the statutory, voluntary, community or private sectors, who undertake or contribute to assessments under the UNOCINI Assessment Framework. UNOCINI provides for an initial assessment and a pathway assessment, which may take several weeks. Assessment under the UNOCINI framework is holistic and covers three domains: the child's needs, capacity of parent or caregiver to meet those needs, and family and environmental factors. The detail of the framework is set out in Section 3.4.2.

Strategies and policies

The most significant strategy in relation to assessment of need is the *Autism Strategy 2023-2028: To Respect, to Listen, to Involve* (2023), which calls for services to be delivered based on need rather than diagnosis.(153) This section covers the following strategy and policy documents:

- Autism Strategy 2023-2028: To Respect, to Listen, to Involve (2023)
- Children and Young People's Strategy 2020-2030 (2020).

Autism Strategy 2023-2028: To Respect, to Listen, to Involve (2023)

This strategy, developed by the Department of Health, notes increasing referrals for autism assessment, which has led to long waiting lists. Many of the actions presented within the strategy are focused on early intervention and support, which is based upon presenting need and getting 'the right support at the right time', rather than placing emphasis on an assessment and diagnosis-driven approach. For example, children and young people must be supported within their educational environment based on their presenting need, regardless of a referral for assessment having been made or a diagnosis having been received.

The strategy states that through provision of accessible step-by-step guidelines, HSC Trusts will improve the provision of relevant information to those referred for assessment. The strategy sets out that the Department of Health will review the current service model to ensure there are consistent service models across Northern Ireland with clear pathways, age-appropriate assessment and intervention processes, and waiting time targets for assessment. At the time of writing, there is an implementation plan for the autism strategy, but as yet there are no clear outcomes.

Children and Young People's Strategy 2020-2030 (2020)

This government strategy sets out a strategic framework for improving the well-being of children and young people in Northern Ireland. It outlines how all government departments, agencies and those who provide children's services will work together to deliver better outcomes for all children and young people. The strategy outlines eight outcomes to be achieved for all children and young people and highlights the key areas of improvement and the pathways to fulfilling these outcomes. These outcomes encompass most aspects of a child's life, for example, their physical and mental health, learning and succeeding, pastimes and leisure, safety and stability, contribution to society, rights, equality, and economic and environmental wellbeing.

While the strategy does not refer specifically to assessment of need, it notes that children with disabilities 'should be fully supported to have access to the same opportunities and life experiences and services as other children.'

3.4.5 Regulation, monitoring and inspection of assessment of need

The Regulation and Quality Improvement Authority (RQIA) is the independent body responsible for monitoring and inspecting the availability and quality of health and social care services in Northern Ireland, and encouraging improvements in the quality of those services.(147) RQIA reviews the performance of Health and Social Care (HSC) Trusts, but there is no specific programme for inspection or monitoring of assessment of need for children with disabilities. In 2013, it carried out a review of community services for children with disabilities; more detail is provided on this in Section 3.4.6.

The Strategic Planning and Performance Group in the Department of Health has oversight of timescales for assessments and numbers of assessments carried out in each HSC Trust. Performance indicators are reported on a monthly basis to the Department, however these are not publicly available.[***]

The Northern Ireland Commissioner for Children and Young People (NICCY) has responsibility for protecting children's rights, as set out in the United Nations

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[***] This information was provided by subject matter experts from Department of Health, Northern Ireland, interviewed on 19 February 2024 to inform this research report.

Convention on the Rights of the Child (UNCRC).(158) ‘Children and young people’ refers to anyone up to the age of 18, or up to 21 if they have a disability, or have been, or are in care. As such, services for children with disabilities fall within the remit of the Children’s Commissioner, for example, in complaints handling, assistance with legal action, and making policy recommendations.

3.4.6 Findings from reviews

An independent review of children’s social care services was published in 2023.(159) The review, commissioned by the Northern Ireland Government, was undertaken as it had been a decade since children’s social care services in Northern Ireland had been examined in depth, and the COVID-19 pandemic had exposed some fragility in the system. The review highlighted ongoing delays in assessment and long waiting lists for services, though with some variance between HSC Trusts. The previous review of children’s social care, undertaken ten years before by the Regulation and Quality Improvement Authority (RQIA), similarly noted variation in the range and quality of services provided to children with a disability.

The reviews detailed in this section are:

- The Report of the Independent Review of Northern Ireland’s Children’s Social Care Services (2023)
- A Baseline Assessment and Review of Community Services for Children with a Disability (2013).

The Report of the Independent Review of Northern Ireland’s Children’s Social Care Services (2023)

This review noted that rates of childhood disability in Northern Ireland are ‘significantly higher than other parts of the UK,’ with particular reference to children’s mental health and autism.(145) The review found that in March 2021, over 5,000 children were waiting for an assessment related to autism, that waiting lists for child and adolescent mental health services (CAMHS) continued to grow, and there were significant variances between Health and Social Care (HSC) Trusts.

The review noted concern among families of children with disabilities regarding the lack of support and the availability of services, and the particular limitations for families living in rural areas. For some services, especially for children with a disability and for mental health services, families noted there were long waiting lists, and services were time-limited or short-term, or as with respite care, heavily rationed or not available at all. Families said they needed less assessment, surveillance and monitoring, and more practical hands-on support. They wanted help when it is needed, rather than being on waiting lists for assessments, and expressed concern that services were only made available when a crisis point is reached and seen as a potential child protection concern.

The review also flagged concerns in the transition from child to adult services when a young person with a disability reaches the age of 18. Transition planning should begin at 14 but this can be challenging due to workforce capacity. The review suggested a number of initiatives to address these issues, including funding a region-wide independent transitions advice and advocacy service, so that young people with a disability and their families are supported and assisted during the transition process, introducing an entitlement to current help and assistance after the age of 18, where an alternative is not in place, and having flexibility with the length of the transition period.

The review noted that, in England, where referral rates to statutory children's social care services are much lower, contacts and information are first screened by multi-agency and multi-professional teams (Multi-Agency Safeguarding Hubs), whereas intake and initial assessment functions in Northern Ireland are undertaken within single agency and largely single profession HSC Trusts' children's social work Gateway Teams. It concluded that this may draw more activity and work into children's social care.

The review found that the diagnosis of autism has increased significantly within Northern Ireland and the demand for assessments related to autism and other neurological disabilities has led to extensive waiting lists for assessment. It noted that a diagnosis is the access route to special educational support and to disability-related social security benefits and possibly to a carer's grant. The review highlighted that children's social care services should be focused on supporting families seeking and needing help and that this help should not need to wait for a diagnosis.

A Baseline Assessment and Review of Community Services for Children with a Disability (2013)

This RQIA report presented a baseline assessment of the role, structure and composition of disability teams for children across the five HSC Trusts.(160) It identified considerable variation in the range and quality of services provided to children with a disability. It recommended that HSC Trusts ensure that the child and their parents or carers are involved in all assessments, discussions about care planning and discharge processes. At the time of writing, considerable variation remains in service provision across the five Trusts.[†††]

[†††] This information was provided by subject matter experts from Department of Health, Northern Ireland, interviewed on 19 February 2024 to inform this research report.

3.4.7 Key Findings

Children with disabilities have a right to an assessment under Article 18 of the Children (NI) Order 1995, and unpaid carers have a similar entitlement to an assessment of their needs. Statutory ‘child in need’ assessments are carried out by Health and Social Care (HSC) Trusts, and Trusts have a statutory duty to provide services necessary to meet identified needs. Assessments generally follow the Understanding the Needs of Children in Northern Ireland (UNOCINI) Framework; it is of note that Northern Ireland is the only UK jurisdiction for which there is no statutory guidance or code of practice for the assessment process or framework. The UNOCINI Pathway Assessment provides a holistic view of a child’s situation, encompassing the child’s needs, parent or caregiver’s capacity to meet those needs, and family and environmental factors which impact upon the child or young person. Once assessment is complete, a social worker will draw up a UNOCINI Family Support Plan. The care plan outlines the needs identified and the services that will be offered by the HSC Trust to meet those needs.

Assessments of special educational needs are separate to this process. A Statutory Assessment and Review Service carries out assessments of special educational needs (SEN) and provides a Statement of SEN where required.

The Regulation and Quality Improvement Authority (RQIA) 2013 review of community services for children with a disability first flagged variation in the assessment process between Trusts, and particularly in the level of service provision following assessment. Variable service provision across regions was again highlighted in the 2023 *Independent Review of Children’s Social Care Services in Northern Ireland*.

Overall, of interest to Ireland is that the evidence from the Northern Ireland experience suggests the need to consider the system as a whole, from early intervention through to assessment of need and on to service provision, in order to provide a ‘continuum of care’. This includes introducing more flexibility and supports around the transition from child to adult services for young people with a disability.

At the time of writing, in Northern Ireland there is currently no system for regularly monitoring the quality of assessment of need. While waiting lists for assessments is not identified as a significant issue, the lack of a system for early assessment and help might delay appropriate intervention. This again underlines the importance of considering the system as a whole, from early help to assessment of need and consistent and appropriate service provision.

3.5 Australia

This section describes the organisation and delivery of assessment of need services in Australia. This section is set out under the following headings:

- overview of assessment of need
- the model of service
- relevant legislation
- standards, guidance, frameworks, strategies and policies
- regulation, monitoring and inspection of assessment of need
- findings from reviews
- key findings.

3.5.1 Overview of assessment of need

In Australia, people with disabilities have a statutory entitlement to access the National Disability Insurance Scheme (NDIS) under the NDIS Act 2013.(161) In 2023, the population of Australia was reported to be 26.8 million people.(162) In 2018 there were 4.4 million people with a disability in Australia, 17.7% of the population. Of those, 357,500 or 7.7% of children under the age of 15 were reported as having a disability.(163) Assessment of need is coordinated by the National Disability Insurance Agency (NDIA), an independent statutory agency. The NDIA implements the National Disability Insurance Scheme (NDIS), which aims to support people with significant and permanent disability, and their families and carers.(164) The implementation of the NDIS is supported by NDIS partners, who assist people to apply for the NDIS and who provide practical information about supports that are available to them.

To access the NDIS, people must undergo two types of needs assessment; a functional capacity assessment and a supports needs assessment. Based on these assessments, the NDIA makes decisions about whether someone is eligible to become an NDIS participant and, if so, how much funding they will receive. The assessment of support needs considers a holistic assessment of the person, their situation, existing supports and their goals for the future. Once the assessments have been conducted and a person has become an NDIS participant, they can coordinate their own access to services or they can get support with this from an early childhood partner, local area coordinator or support coordinator.

There are no specific standards in place for assessment of need, however standards are in place for the services provided following assessment. *NDIS Practice Standards* *and Quality Indicators* (2021) and the *National Standards for Disability Services* (2013) specify the quality standards to be met by registered NDIS providers.(165,166) The *NDIS Code of Conduct* applies to all providers that provide NDIS supports.(167) The NDIS Commission is an independent agency that is responsible for the regulation of NDIS providers, and the registration requirements for service providers seeking to become registered NDIS providers.[‡‡‡] .(168)

A review of the NDIS, published in 2023, highlighted a number of issues with the access and planning process for the NDIS and noted that the scheme is considered complex and confusing.(169) Following this review, the system is undergoing major reform and a new pathway for access to the NDIS was proposed that involves a more holistic approach to assessment of need.(169)

3.5.2 The model of service

In Australia, responsibility for the organisation of assessment of need lies with the National Disability Insurance Agency (NDIA). This section sets out the model of service under the following headings:

- structure and governance of assessment of need
- scope of assessment of need
- assessment of need process
- appeals process.

Structure and governance of assessment of need

Australia is a federation of six states which, together with two self-governing territories, have their own constitutions, parliaments, governments and laws.(170) The National Disability Insurance Agency (NDIA) is an independent statutory agency. Its role is to implement the National Disability Insurance Scheme (NDIS), which aims to support a better life for Australians with a significant and permanent disability and their families and carers.(164) The NDIS has funding and governance shared among all governments. All Australian governments are involved in decisions relating to the scheme's policy, funding and governance.(171)

The implementation of the NDIS is supported by NDIS partners. Early childhood partners are professionals who work with children younger than six with developmental delay and younger than nine with disability and their families. Early childhood partners employ early childhood educators and allied health professionals

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[‡‡‡] NDIS service providers are a specific cohort of providers who meet requirements and register with the commission. People in receipt of financial support can choose to use other agencies who are not registered if they wish.

who help children and their families to access supports and services that are tailored to the child's individual needs and circumstances. Local area coordination partners are community-based organisations that are funded by NDIS to help deliver local area coordination services in some parts of Australia. Local area coordination partners work with people with disability aged nine to 64. For most people in this age range, a local area coordinator will be their main point of contact for the NDIS. Remote community connectors, also known as NDIS connectors, play a key role in helping to deliver the NDIS in remote and very remote communities.(172)

Scope of assessment of need

Assessment of need is conducted as part of the process of applying to the NDIS and the process of NDIS planning which includes goal setting and budget allocation. The NDIS is available to those aged between nine and 65 years old.(173) For children younger than nine years old, an early childhood partner can provide supports to children before they apply, and let families know if the NDIS is right for their child. It is available to those living in Australia who are Australian citizens, permanent visa holders and protected special category visa holders.

There are two pathways to enter the NDIS:

- **The disability pathway**

  The NDIS is available to people who have a disability that is attributable to an impairment that is permanent, or likely to be permanent, and that results in substantially reduced functional capacity. The impairment may be intellectual, cognitive, neurological, sensory, physical, or psychosocial.

- **The early intervention pathway**

  A person can access the NDIS through the early-intervention requirements, without having substantially reduced functional capacity. Instead, the early-intervention requirements consider the likely trajectory and impact of a person's impairment over time, and the potential benefits of early intervention on the person's functional capacity, for example developmental delay in a child.(174)

When a person applies to the NDIS, they have to meet legislative criteria to show that they are eligible for either the disability pathway or the early intervention pathway. People who access the NDIS will undergo two types of assessment:

- **A functional capacity assessment**

  An initial assessment, known as a functional capacity assessment is conducted. The functional capacity assessment evaluates an individual's ability to perform everyday tasks, determining if a person has met the criteria for substantially-reduced functional capacity. This assessment looks at the domains of communication, socialisation, learning, mobility, self-care and self-management. This assessment is generally conducted by a professional outside of the NDIA who provides a report to the NDIS. If a person applies to the NDIS without this assessment, the NDIA can conduct an interview where the applicant will describe their level of function.

- **A support needs assessment**

  Once a person has access to the NDIS, they enter into the planning process. This involves an assessment of support needs, which is not a formal assessment but part of the planning process. Often the person submits reports from their treating professionals to provide evidence for the supports that they need. The NDIS planner discusses support needs with the person and uses all the collected information to calculate a personal budget, with which the person can purchase supports. External assessments of support needs can be funded through the person's budget, once they have been accepted to the NDIS.

Children and young people with special educational needs

Assessments for children and young people with special educational needs are a separate process. Schools can refer students for assessments to help them find out if a student is eligible to apply for support under the Program for Students with Disabilities (PSD). All assessments are carried out by qualified and fully registered psychologists and speech pathologists. Assessments Australia is contracted to conduct these assessments on behalf of the Department of Education.(175) This programme sits within the Department of Education.(176) The assessment categories are:

- intellectual disability
- severe language disorder with critical educational needs.(175)

Assessment of need process

The stages of the NDIS process that include assessment of need include application to the NDIS and NDIS planning. The process for assessment of need is described below in relation to:

- the process of applying to the NDIS – including functional capacity assessment
- the process of NDIS planning – including assessment of support needs.

Applying to the NDIS

A person can apply to the NDIS by completing an eligibility checklist and an access request form and returning these to the NDIA. The application must include evidence to prove: disability, age, Australian citizen or permanent resident status and residence in Australia.(177)

When a person applies to the NDIS, they have to meet legislative criteria to show that they are eligible for either the disability pathway or the early-intervention pathway.(178) An applicant's 'treating professional', for example their GP, other medical or allied health professional, has a role in providing objective evidence that the person meets these criteria. They can provide this information by completing the 'treating professional' section of the access request form and by attaching relevant forms, assessment reports and other relevant information. This will usually include a functional capacity assessment. While there is no set assessment tool in place for this, there are recommended tools such as the World Health Organisation Disability Assessment Schedule (WHODAS) and the Paediatric Evaluation of Disability Inventory Computer Adaptive Test (Pedi-CAT).(179,180) The functional capacity assessment looks at domains of communication, socialisation, learning, mobility, self-care and self-management.

For children under the age of nine, early childhood partners carry out more specialised assessments and help with applications for the NDIS. Children under the age of six do not require a diagnoses to join the scheme. If the applicant has a psychosocial disability, the treating professional can also choose to complete an evidence of psychosocial disability form, which has prompts specific to psychosocial disability. As part of the application process, the NDIA also collects information about the person's goals, their living arrangements, their current supports, assistive technology and any current or future plans for study and social activities. Once the documentation is received, the applicant will be contacted within 21 days to be told if they are eligible or to ask for further information. The NDIA allows 28 days to explain a decision, for example, about whether a person is eligible to access the NDIS.(181)

NDIS planning

Once a person has access to the scheme, the NDIA look at planning and support needs. The NDIS planner will assess the support needs of the person, taking into account any information provided by their healthcare providers. Information is generally gathered using internal forms such as the Research and Environmental Circumstances Form and the Planning Conversation Tool.[§§§] The assessment of

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[§§§] The Research and Environmental Circumstances Form and the Planning Conversation Tool is an internal document used by NDIA and at time of writing was not publically available.

support needs considers a holistic assessment of the person, their situation, existing supports and their goals for the future. To support the assessment, reports from a range of sources can be used, which may include teachers, medical and allied health professionals.

The NDIS planner uses the following information to help them decide what NDIS funded supports to include in a person's plan:

- the information provided during application to the NDIS
- a person's community connections plan if they have one (community connections is a service available through the NDIS, it can include things like help to access information, talking about how to access mainstream and community supports, or help to apply to the NDIS)
- any reports from doctors or allied health professionals
- other assessments, for example from other government agencies or disability service providers
- other relevant information held by the NDIA about the person's support needs
- any other information about the person, including about their lived experience.(182)

The NDIA will develop the person's 'plan', including a budget from which the person can purchase supports. The NDIA create the plan based on the support needs directly related to the person's disability. The plan will include information about:

- the person and their living situation
- the person's goals, or things they want to work towards
- who supports the person, for example their family, friends, community, and other government services
- any NDIS supports
- how the person can use their NDIS funding
- who will manage their NDIS funding
- when the NDIA will review and change the plan.(182)

The NDIA allows 56 days to approve a plan and seven days are allowed for the NDIA to give the person a copy of their plan, once it is approved.(181) If the person is not happy with the plan or a decision that has been made, they have three months to ask for an internal review, this can be done by completing a ‘request for review of decision form’.(183)

Once a person’s plan is in place, they can coordinate their own access to services or they can get support from an early childhood partner, local area coordinator or support coordinator to support them with service coordination. Services are provided by service providers, defined as a person, business or organisation who delivers NDIS funded supports to participants. People can use NDIS registered providers or they can access other non-registered providers and can pay for these using their allocated budget.

Appeals process

The NDIS Appeals Program helps people with disability, and other people affected by reviewable decisions of the NDIA. The programme helps people access support when seeking the review of a decision through the Administrative Appeals Tribunal (AAT). To access the NDIS Appeals Program, an individual must have already applied to the NDIA for an internal review and received an outcome. Once an outcome to an internal review has been provided, individuals can access the NDIS Appeals Program to get help with undertaking an external review at the AAT. An application for an AAT review must be made within 28 days of receiving the NDIA decision. There are two types of supports available under the ongoing NDIS Appeals Program for people appealing internal NDIA decisions before the AAT:

- access to a skilled disability advocate who acts as a support person
- access to funding for legal services, where there is wider community benefit and or disadvantage that would substantially benefit from legal representation.(184)

Support persons are also National Disability Advocacy Program (NDAP) disability advocates. They are available in every state and territory. While the focus of the NDIS Appeals Program is advocacy support, individuals may also be able to access legal services through the Legal Aid Commission in their state or territory. All NDIS Appeals Program supports are free of charge.(184)

3.5.3 Relevant legislation

The National Disability Insurance Scheme Act 2013 (NDIS Act) is the legislation which establishes the National Disability Insurance Scheme and the National Disability Insurance Agency (NDIA).(161) Among other things, the NDIS Act sets out:

- the objects and principles under which the NDIS will operate

- how a person can become a participant in the NDIS and access services and funding
- how a participant's individual, goal-based plan is prepared and reviewed, including how the NDIA approves the funding of reasonable and necessary supports
- how a provider can become a registered NDIS provider
- the governance arrangements for the NDIA, including its Chief Executive Officer (CEO), board, independent advisory council, and actuaries
- a process for internal and external review of certain decisions made under the NDIS Act.

The NDIS Rules 2018 are legislative instruments made under the NDIS Act. They set out the more detailed operation of the NDIS and accompany - and should be read in conjunction with - the NDIS Act. Among others, there are NDIS Rules on becoming a participant, supports for participants, plan management and registered providers of supports.(185)

The NDIA's statutory functions are set out in Section 118 of the NDIS Act. In summary, the main statutory functions are:

- delivering the NDIS so as to, amongst other things, support the independence, and social and economic participation, of people with disability and enable people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports
- managing, and advising and reporting on, the financial sustainability of the NDIS
- developing and enhancing the disability sector
- building community awareness of disabilities and the social contributors to disabilities
- collecting, analysing and exchanging data about disabilities and the supports for people with disability
- undertaking research relating to disabilities, the supports for people with disability and the social contributors to disabilities.

3.5.4 Standards, guidance, frameworks, strategies and policies

There are no specific standards, guidance, frameworks, strategies or policies that specifically apply to the process of assessment of need in Australia. However, standards have been developed to drive improvement in services that provide care to people with disabilities. These include:

- NDIS Practice Standards and Quality Indicators (2021)
- NDIS Code of Conduct
- National Standards for Disability Services (2013).

NDIS Practice Standards and Quality Indicators (2021)

The NDIS Practice Standards and Quality Indicators have been developed by the NDIS Quality and Safeguards Commission. They specify the quality standards to be met by registered National Disability Insurance Scheme (NDIS) providers to provide supports and services to NDIS participants.(165) They include standards on:

- rights of participants and responsibilities of providers
- governance and operational management
- the delivery of supports
- the environment in which supports are delivered.

More detail on these standards is provided in Section 3.5.5.

NDIS Code of Conduct

The *NDIS Code of Conduct* promotes safe and ethical service delivery, by setting out expectations for the conduct those delivering services to NDIS participants.(167) The *NDIS Code of Conduct* applies to both registered NDIS providers and unregistered NDIS providers, and their employees. The *Code of Conduct* requires providers and employees who deliver NDIS supports to:

- act with respect for individual rights to freedom of expression, self-determination, and decision-making in accordance with relevant laws and conventions
- respect the privacy of people with disability
- provide supports and services in a safe and competent manner with care and skill
- act with integrity, honesty, and transparency
- promptly take steps to raise and act on concerns about matters that might have an impact on the quality and safety of supports provided to people with disability

- take all reasonable steps to prevent and respond to all forms of violence, exploitation, neglect, and abuse of people with disability
- take all reasonable steps to prevent and respond to sexual misconduct.

National Standards for Disability Services (2013)

The *National Standards for Disability Services* help to promote and drive a nationally consistent approach to improving the quality of services. They focus on rights and outcomes for people with disability. The national standards were developed by the Department of Social Services.(166) These standards apply to a broad range of services, including NDIS providers.

3.5.5 Regulation, monitoring and inspection of assessment of need

There is no specific monitoring of the assessment of need process in Australia. However, there is regulation of service providers who provide National Disability Insurance Scheme (NDIS) services. The NDIS Quality and Safeguards Commission (NDIS Commission) is an independent agency that is responsible for the regulation of NDIS providers, and the registration requirements for providers seeking to become registered NDIS providers.(168) The NDIS Commission's regulatory powers and functions are set out in the NDIS Act 2013 (the Act) and NDIS Rules 2018.

The NDIS Commission has developed *NDIS Practice Standards and Quality Indicators*.(165) They specify the quality standards to be met by registered NDIS providers to provide supports and services to NDIS participants. The outcomes listed in the *NDIS Practice Standards and Quality Indicators* are included within the NDIS Rules 2018.

The NDIS Commission monitors registered providers for compliance with the conditions of their registration. Most registered providers must undergo a periodic audit that assesses their performance against the *NDIS Practice Standards and Quality Indicators*.

The NDIS Commission also investigates complaints and reports of non-compliance with the NDIS Practice Standards, *NDIS Code of Conduct* and other quality and safeguarding requirements where they apply. This includes unregistered providers' compliance with the NDIS Code of Conduct.(186)

The compliance and enforcement actions available to the NDIS Commission are:

- administrative (these actions include education, corrective action requests, warning letters, compliance notices, infringement notices, enforceable undertakings, varying, suspending or revoking registration, and bans)

- court-based (these actions include injunctions, taking action to enforce an undertaking, and civil penalties).

The NDIS Commission maintains a NDIS provider register online. This register contains information on the compliance and enforcement actions taken by the NDIS Commission, including banning orders, compliance notices, and suspensions of registration for specific providers only. It is available publically.

3.5.6 Findings from reviews

This section provides detail on a number of reviews that have been conducted in relation to the National Disability Insurance Scheme (NDIS). These reviews include:

- Working together to deliver the NDIS (2023)
- Joint Standing Committee on the National Disability Insurance Scheme - Independent Assessments (2021)
- Review of the National Disability Insurance Scheme Act 2013 (2019).

Working together to deliver the NDIS (2023)

The Minister for the NDIS announced a review of the NDIS in 2022. *Working together to deliver the NDIS* (the NDIS Review) looked at the design, operations and sustainability of the NDIS. It also looked at ways to make the market and workforce more responsive, supportive and sustainable. An overarching goal of the NDIS Review was to put people with disability back at the centre of the NDIS. It aimed to help restore trust, confidence and pride in the NDIS.(187) Trust in the NDIS had been damaged due to ongoing operational issues, highlighted in earlier reviews, such as the inquiry into Independent Assessments – Report of the Joint Standing Committee on the NDIS (2021) and the *Review of the National Disability Insurance Scheme Act 2013* (2019).(188,189)

Problems with the NDIS access and planning process (including assessment of need) were the most commonly raised issues during this review. At best, people described the planning process as confusing and frustrating. At worst, it was described as traumatic.(169) The review found a lack of trust between participants and the National Disability Insurance Agency (NDIA). It was also found that, before the NDIS, disability supports were largely generic and did not always cater to people's individual needs and circumstances. In an attempt to respond to the diversity of people's needs and circumstances, the scheme has become very complex and confusing.

The review notes that in 2021, there was an attempt to reform the assessment process, with the introduction of independent assessments (a proposed new process for assessment of need). This attempt at reform was not done in consultation with the disability community and, as a result, was unsuccessful and provoked considerable anger and anxiety. The *Working together to deliver the NDIS* review proposes a new participant pathway, detailed in Table 2 below.(190)

Table 2. NDIS review; proposals for a new participant pathway

Participant pathway	Participant experience	Experience enabler
Find out about disability and supports available	Mainstream services are informed and equipped to refer people with disability to navigators and or the right information to help them get the supports they need.	Mainstream services will understand their responsibilities and be connected with the NDIS and foundational supports.
Access a navigator	Navigation is consistently available for all people with disability across Australia and delivered locally by people who are connected and understand local communities.	Navigators are run locally, but are accountable to nationally consistent training and oversight.
Access inclusive local and mainstream support	Navigators will help people to find and coordinate support they need in their community and achieve what is important to them.	Mainstream supports are more accessible and foundational supports will be more available locally.
Find out about the NDIS	Navigators and the NDIA will help people with disability understand what the NDIS is, who it is for and how to make an access request if required.	The same accessible information will be available to participants, navigators and the NDIA.
Apply to the NDIS	Applicants can use a fairer and simpler approach to making access requests and providing evidence to support their request. They will have access to a navigator and mainstream and local supports while their request is being processed.	Evidence required for access will be clear and proportionate.

Complete assessments to understand need & set a budget	A comprehensive assessment of need is undertaken by a skilled assessor. This will include a discussion of the risks in a participant's life and what safeguards could be put in place in response. Participants will have as long as they need to ensure they are understood and will be able to view the assessment and add missing information before the budget is set.	Skilled Assessors will use self-reporting and strength-based interviews to assess need.
Receive a budget	Participants receive approved funding in a flexible budget and, if eligible, a home and living budget and stated supports for assistive technology, equipment, and other one-off capital costs.	Funding allocation process will be designed with people with disability and the sector.
Develop a plan of action	Participants are supported by navigators to develop a plan of action to use their budget in a way that meets their needs, and to implement safeguards to manage risk.	Navigators have access to specialist advice.
Access supports	Navigators can help identify potential supports and providers that may meet the needs of participants – this could mean helping to switch providers. Navigators help coordinate supports for those who need it.	Online platform supports participants and navigators to find quality providers in their area.
Check-in on progress	Participants get the level of support they need to make sure supports are working for them and that they have effective safeguards in place. Participants are trusted to spend their funds in a way that helps them live an inclusive life. Navigators help to	Data is collected through the electronic payments system.

	quickly respond to change in circumstances.	

The review notes that access to the NDIS should be based first and foremost on significant functional impairment and need, and only secondly on medical diagnosis. A focus on functional impairment should enable multiple disabilities to be considered, which, when taken together, result in significant functional impairment. The review recommends significant reform to the access process to make it more equitable. This includes making the process of applying for the NDIS clearer and simpler, clarifying definitions of key eligibility criteria, and standardised approaches to determine whether eligibility criteria are met.

The review also notes that assessments should be the basis of long-term plans and forward-looking, for instance, taking account of progressive conditions. They should be more flexible for participants and take account of life transitions, including finishing school, moving out of home or seeking employment. Planning meetings currently combine an assessment of support need, budget setting and planning. The review notes that this is a complicated and stressful experience for people with a disability. The review recommends changing what is now described as planning into three separate steps to create a process that is clear, transparent and focused on support needs. The three steps are:

1. A transparent process should be in place for information gathering, as part of the assessment of support need. This should aim to ensure a participant’s disability-related support needs are at the centre throughout. The person leading the assessment should be the person agreeing the NDIS budget with the participant. They should be an agent or employee of the NDIA, with high level expertise in disability, and spend sufficient time with participants so they feel heard. Only essential information should be collected.

2. Evidence to support the assessment should come from the participant, any treating professional if required, and take into account holistically the participant's life circumstances. Where assessments may assist the process, they should be transparent, valid, accepted by people with disability and appropriate to the circumstances of the participant.

3. Where additional information is needed, the NDIA should commission and pay for professional assessments and reports.

Joint Standing Committee on the National Disability Insurance Scheme - Independent Assessments (2021)

The Joint Standing Committee on the National Disability Insurance Scheme was established by resolution of the House of Representatives in 2019. The committee initiated an inquiry into the proposed introduction of Independent Assessments inquiry following concern expressed in the community.(188) Independent assessments were a proposed new process for assessment of need.

In April 2021, the Minister for the NDIS announced that the government would pause the rollout of independent assessments, pending closer consideration of the outcomes of pilot programmes. In July 2021, following a meeting with state and territory disability ministers in the Disability Reform Council, and the release of advice from the Independent Advisory Council, the Minister announced that independent assessments would not proceed.

The NDIA noted that feedback on independent assessments had been 'mixed', acknowledging that 'people with disability are anxious with how assessments will be carried out, as well as how that information will be used to determine their access to, and ongoing eligibility for the NDIS'. Concerns raised included the skills, experience and background of assessors, including that the assessor would not know the individual, and that assessors should have knowledge of particular disability types. The report noted that many 'people expressed a strong preference for having their treating health professionals completing assessments, rather than being referred to an assessor with whom they are not familiar'.

The report outlined that the committee welcomed the announcement that the government would not be proceeding with independent assessments in their proposed form, and was taking time to consult in a meaningful way. The report recommended that consultations with medical and allied health professionals for the purposes of access to the NDIS should be carried out by health professionals nominated by participants and that the process should be holistic and multidisciplinary. It was also recommended that all assessment tools that the NDIA proposes should be subject to rigorous consultation with people with disability, disability representative organisations, and relevant health and allied health practitioners before the NDIA decides to implement them.

Review of the National Disability Insurance Scheme Act 2013 (2019)

In June 2019, the Australian Government commissioned a review of the NDIS Act, with a focus on streamlining NDIS processes and removing red tape for participants and providers. Specifically, the review examined participants' experiences of the NDIS and opportunities for improvement, and honours a commitment made during the 2019 Election campaign to introduce a Participant Service Guarantee.(189)

Feedback to the review showed that participants were frustrated about delays with the NDIS and felt that there was a lack of clarity around how the NDIA made decisions.(191) Participants found the NDIS complex and confusing to navigate and felt that NDIA staff did not understand disability or appreciate the challenges people with disability face as part of everyday life.

The review also found that there was a need to improve legislation to strengthen participant focus and noted that the NDIA should publish a greater range of policy information, including in a wider range of accessible formats, to help participants better understand why certain decisions have been made.

The government published a response to the review and stated that it supported in principle the recommendations made in the review report.(192)

3.5.7 Key findings

In Australia, assessment of need is coordinated by the National Disability Insurance Agency (NDIA). The NDIA implements the National Disability Insurance Scheme (NDIS), which aims to support people with significant and permanent disability and their families and carers.(193) The National Disability Insurance Scheme Act 2013 (NDIS Act) is the legislation which establishes the NDIS and the NDIA.(161) The NDIS Act is holistic in nature and aims to support the independence, and social and economic participation of people with disability and enable people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports.

People who access the NDIS will undergo two types of assessment; a functional capacity assessment and a support needs assessment. The functional capacity assessment evaluates an individual's ability to perform everyday tasks, determining if they meet the criteria for NDIS funding. While there is no set assessment tool in place for this, there are recommended tools such as the World Health Organisation Disability Assessment Schedule (WHODAS) and the Paediatric Evaluation of Disability Inventory Computer Adaptive Test (Pedi-CAT).(179,180) Once a person has access to the NDIS, they will enter into the planning process. This involves an assessment of support needs. The assessment is holistic in nature and has a strong focus on the person’s goals and aspirations. There is a focus on personal autonomy, in that, a person can use their budget to choose and coordinate their own services.

There are no specific standards or guidance that apply to the assessment of need in Australia and the process is not monitored or regulated.

As a number of reviews have taken place in relation to the NDIS in recent years, there are a number of lessons to be learned for Ireland. The holistic nature of assessments, with a strong emphasis on the person, their life and their goals, is a key learning. While the recent NDIS review in 2023 found a number of issues with the assessment process, Australia is now working towards assessments that are based first and foremost on significant functional impairment and need and only secondly on medical diagnosis. Going forward, assessments should be the basis of long-term plans and forward looking, for instance, taking account of progressive conditions. They should be more flexible for participants and take account of life transitions, including finishing school, moving out of home or seeking employment. The review also indicated a need for a more systematic approach to assessments, including standardisation of the assessment tools used.

The inquiry into Independent Assessments – Report of the Joint Standing Committee on the NDIS (2021) highlighted that assessments can be a source of stress and anxiety for people and the importance of providing assessments that are fit for purpose and acceptable to those being assessed.(188) Assessment tools should be subject to rigorous consultation with people with disability, organisations representing people with disabilities, and relevant health and social care practitioners before being implemented.

While there are positive aspects to the current system for assessment of need in Australia, including the holistic nature of assessments, the system is considered complex and confusing. The system is currently undergoing major reform on foot of the recent reviews of the NDIS. A key focus of this reform is ensuring the person is at the centre of the process and that a holistic view is taken of the person, their life and their goals for the future.

3.6 New Zealand

This section describes the organisation and delivery of needs assessment and service coordination for children with disabilities in New Zealand and the effectiveness of these services. This section is set out under the following headings:

- overview of assessment of need
- the model of service
- relevant legislation
- standards, guidance, strategies and policies
- regulation, monitoring and inspection of assessment of need
- key findings.

3.6.1 Overview of assessment of need

In New Zealand, people with disabilities have a statutory entitlement to avail of state-funded support services if they undergo a needs assessment.(194) The estimated resident population of New Zealand in 2024 is 5.3 million people.(195) In 2013, 24% of the New Zealand population were identified as people with a disability, a total of 1.1 million people.(196)

The Needs Assessment Service Coordination Association (NASCA) is a not-for-profit organisation contracted by the Ministry of Health to facilitate needs assessment, service planning and service co-ordination for people with disabilities. Needs Assessment Service Coordination (NASC) agencies organise needs assessments and service coordination process at local level.(197)

Needs assessment in New Zealand is a process of determining the current abilities, resources, goals and needs of a person and identifying which of those needs are the most important. The concept of needs assessment is based on a belief that disabled people and their families can be trusted to define their own needs.(198) The aim of the needs assessment is to help a person to stay independent or get the best possible help to maintain their quality of life.(199) Following a needs assessment, the NASC identifies services or supports that the person is eligible for, to help them meet their goals and needs, and undertakes service planning and service coordination based on the individual's need.

NASCs are required to comply with *Social Sector Accreditation Standards* (SSAS) and are monitored by the Standards and Monitoring Services (SAMS), against these standards and the Enabling Good Lives (EGL) approach.(200,201,202) SAMS is a national organisation governed by people and families with disabilities. Recent reviews of the health workforce in New Zealand reported a workforce that is under strain and identified barriers to recruiting people into the disability workforce, gaps in training programmes and issues with retention across the sector.(203,204)

3.6.2 The model of service

The Needs Assessment Service Coordination Association (NASCA) is responsible for needs assessment and service coordination for children and adults with disabilities in New Zealand. This section sets out the organisation and delivery of needs assessment under the following sub-headings:

- structure and governance of assessment of need
- scope of assessment of need
- assessment of need process.

Structure and governance of assessment of need

Manatū Hauora – the Ministry of Health (MOH) has overall responsibility for the management and development of the health and disability system in New Zealand. In working towards Pae Ora (healthy futures) for all New Zealanders, the MOH works with a number of key government agencies and organisations. This section provides a brief description of the organisations that are significant to needs assessment and service coordination in New Zealand. The key organisations are:

- Whatu Ora - Health New Zealand
- Whaikaha – the Ministry of Disabled People
- Needs Assessment Service Coordination Association (NASCA).

Health New Zealand is the government agency that funds a range of health services, including disability support services through the Needs Assessment Service Coordination (NASC) agencies. In 2022, the Ministry of Disabled People was established to improve the lives of people with disabilities in New Zealand and provide them with a more independent future.(205) They are responsible for the commissioning and delivery of disability support services to children and adults with disabilities under the age of 65 years.

Local NASC agencies facilitate needs assessment, conduct service planning and co-ordination and manage resource allocation within a defined budget. Children and Adult NASCs work with people with disabilities generally under the age of 65 years. Each part of New Zealand may have several NASC services; there are 15 younger peoples NASCs based throughout New Zealand.(197) The size of a NASC team depends on the population, size and caseload. A worker might carry a caseload of

250 to 400 people. Each NASC is provided funding for the provision of disability support services by the relevant funding body. The Ministry of Disabled People is responsible for funding disability support services to people who have a physical, intellectual or sensory disability or a combination of these, mainly under the age of 65 years.(206)

Scope of assessment of need

In order to be considered for publicly-funded services, be it free or subsided, a person must first meet one of the criteria in the Health and Disability Services Eligibility Direction 2011; they must also be in New Zealand and be either a citizen or a holder of certain visas to have the right to apply for publicly-funded services.(207) A person can apply for a needs assessment by a NASC if:

- they live in the community and require help to maintain their independence at home
- their health circumstances have changed and they require a re-assessment of their needs
- their current support services package no longer meets their need and they are unable to live safely in the community, long-term residential care is available for those with a high level of care needs
- they are a resident in a care facility and wish to apply for a needs assessment.

NASCs work with children and adults with disabilities to establish eligibility to publicly-funded services, and to help identify their needs and outline what disability support services are available. Disability is interpreted to arise from a congenital condition or one acquired before the age of 65. A person with a disability is defined by the Ministry of Health as:

> someone who has been identified as having a physical, intellectual, or sensory disability (or a combination of these) which is likely to continue for a minimum of six months and result in a reduction of independent function to the extent that ongoing support is required.(208)

To access disability funding, a person needs to meet certain criteria. There is no lower age limit for needs assessment. New Zealand follows a social model of disability; if a person is accepted to have a disability, a diagnosis of the underlying syndrome is not required before accessing services.(209)

Children with Special Educational Needs (SEN) are not under the remit of NASCs; the Ministry of Education is responsible for providing support and access to education.

Assessment of need process

NASCs are required to undertake needs assessments and service coordination for people seeking access to disability support services. The needs assessments and services co-ordination processes are separated to ensure objectivity and transparency through the process of identifying the person's needs. Elements of the NASC process are discussed below as follows:

- needs assessment
- service coordination.

Needs assessment

To apply for a needs assessment, a person first makes contact with their local NASC. A NASC must establish if the person is eligible to receive state-funded services.(207,210) If the person is not eligible and the referral is declined, the NASC must redirect the person with a disability or referrer to the service best able to assist them.(198) An application can also be made by a family member, or by referral from any other person, such as a general practitioner or if the person is in hospital, by the hospital staff.(199)

The Support Needs Assessment and Service Co-ordination Policy, Procedure and Information Reporting Guidelines set out timeframes that NASCs are required to work to.(198) Needs assessments are carried out within 24 hours from acknowledgment of an application in a crisis situation, within 48 hours depending on the degree of urgency or generally within 20 days. During a needs assessment, the assessor adopts a person-centred approach and works with the person, and their family if appropriate, to work out the care they need. An assessor visits the person to determine:

- their health
- the level of support from family and friends
- how they are coping with day-to-day tasks
- how they feeling about the future.(199)

The NASC consider a person's abilities, resources, goals and needs, and which of these needs are the most important.(210) The purpose of the process is to decide what is needed to maximise a person's independence. A person's needs will also include, where appropriate, the needs of their family and carers; their recreational, social and personal development needs; their training and education needs; and their vocational and employment needs. During a needs assessment, the NASC work to the Enabling Good Lives (EGL) principles by asking a number of questions to establish what a good life would look like for the person (EGL is discussed in more detail in Section 3.6.4). During the assessment the person is asked:

- To explain who they are and what is important to them? For example, what are their hopes and aspirations?
- What needs to change, if anything, to do more of what they love and help them live a good life? For example, what do they need more or less of?
- Which are the most important changes, if they can't have everything, where would they like to start?
- What help do they need to make those changes? For example, how much help do they need to arrange supports or how much do they want to do themselves?
- When and how should a review take place to see if this is working for them?

The level of detail required in the needs assessment depends on the individual's situation.(198) The outcome of the process is a comprehensive needs assessment report.

If required, the assessment facilitator may refer the person for a specialised assessment. This is required when a person's needs require further investigation and a referral is made with the person's consent. Such assessments are generally funded directly by the Ministry of Health and are not a charge on the NASC budget. Specialised assessments may include, but are not limited to, clinical, diagnostic or other assessment.(209) There is no time limit on the validity of a needs assessment and if a person is changing NASC region, information is transferred to another NASC within five working days of the transfer request being received.(209)

Service coordination

The NASC is required to undertake service planning and service coordination. The needs assessments and services coordination processes are separated to ensure the availability or constraints of resources is not considered in assessing the needs of a person with a disability.(198) A NASC may maintain this boundary by having two different people carry out the two functions of a needs assessment facilitator and service coordinator. Where this is not possible, one person follows through the whole process. In all cases, information must be transferred in a way to ensure that the person with the disability is not required to repeat information.(198)

Service coordination is required to be conducted within 10 days of completing the needs assessment in the majority of cases.(209) The task of service coordinator is to identify and discuss with the person their desired outcomes and to develop a support plan that meets the person's needs.(209) The coordinator ensures that, wherever possible, the person has a choice of service options, including involvement of family, community, voluntary or private (personally funded) services. Where appropriate services are not available, the coordinator and the person consider other possible options for meeting identified support needs.

Staff members conducting needs assessments and service coordination are not required to be health professionals, however each NASC has a responsibility to ensure that staff are supported to develop and maintain competence and undertake formal training and qualifications as they are developed.(209)

The NASC is also responsible for providing intensive service coordination for the small number of people with high and complex needs. Intensive service coordination requires an ongoing relationship between the person and the coordinator. (209)

If the person agrees to the recommendations set out in the support plan, the NASC facilitates the commencement of services and supports. If funded services are needed, these services are delivered by contracted providers. These services could include help in the home (such as housework), help with personal care (such as showering), respite care, support for independent living, and many others.

In the majority of situations, most people's needs will be successfully met through the standard range of services, however discretionary funding arrangements can be made through the NASC to provide more flexible and innovative supports.(209)

The NASC determines a timeframe with the person to review their support package to ensure it is still relevant and their desired outcomes are being achieved. Based on the person's needs, a review occurs every 12 to 18 months.(198) For those with high or complex needs, the review period may be shorter and more frequent.(198) If a service is not meeting a person's needs or their eligibility for supports has changed, a person may seek a review at any time.(198)

Appeals process

A review of the assessment can be sought from NASC, or from the MOH if a person does not agree with the assessment outcome(199). There are four levels to this process, set out below:

1. Level 1 – the assessor reviews the assessment with their team
2. Level 2 – the assessor's manager reviews the assessment
3. Level 3 – the assessment is peer-reviewed by a NASC in a different location
4. Level 4 – the issue is referred to the MOH.

Separately, complaints and feedback can be provided to NASC. Those unhappy with the statutory-funded disability supports and services they have received can make a complaint or provide feedback about their experience to the Ministry of Disabled People.

3.6.3 Relevant legislation

The New Zealand health and disability system's statutory framework is made up of over 20 pieces of legislation, the most significant are the Health Act 1956 and the Pae Ora (Healthy Futures) Act 2022. This section describes the key legislation in relation to needs assessments for children, these are:

- Health Act 1956
- The Code of Health and Disability Services Consumers' Rights 1996.
- Pae Ora (Healthy Futures) Act 2022.

Health Act 1956

The Health Act 1956 sets out the roles and responsibilities of individuals to safeguard public health.(211) The Act sets out the functions of the Ministry of Health (MOH) and local authorities in improving, promoting and protecting public health. Public health provisions include environmental health, infectious diseases, health emergencies, and the national cervical screening programme.(212)

The Code of Health and Disability Services Consumers' Rights 1996

The Code of Health and Disability Services Consumers' Rights, 1996, (the Code) establishes the rights of consumers, and the obligations and duties of health and disability providers to comply with the Code.(213) It is a regulation under the Health and Disability Commissioner Act. The Code sets out the rights of consumers, listed below:

1. Right to be treated with respect.
2. Right to freedom from discrimination, coercion, harassment, and exploitation.
3. Right to dignity and independence.
4. Right to services of an appropriate standard.
5. Right to effective communication.
6. Right to be fully informed.
7. Right to make an informed choice and give informed consent.

8. Right to support.
9. Rights in respect of teaching or research.
10. Right to complain.

The onus is on the provider to prove that they have taken reasonable actions to give effect to the rights, and comply with the duties in this Code.(213)

Pae Ora (Healthy Futures) Act 2022

The Pae Ora (Healthy Futures) Act 2022 took effect on 1 July 2022, transforming the health sector in New Zealand.(214) Aimed at creating a more equitable, accessible, cohesive and people-centred system, the Act provides for the public funding and provision of services in order to:

- protect, promote, and improve the health of all New Zealanders
- achieve equity in health outcomes among New Zealand's population groups, including by striving to eliminate health disparities, in particular for Māori; and
- build towards Pae Ora (healthy futures) for all New Zealanders.

The Act established three new entities and the dis-establishment of the 20 former District Health Boards (DHBs). The newly-established bodies include a new Public Health Agency within the MOH to lead and strengthen public health, Health New Zealand as the national organisation to lead and coordinate delivery of health services across the country and the Māori Health Authority as an independent statutory authority to drive improvement for Māori.

The Act sets out the objectives and functions of Health New Zealand, including their requirement to provide or arrange for the provision of services at a national, regional, and local level and to set requirements and specifications for publicly funded services. The Act also specifies the requirement of the MOH to develop a suite of health strategies, including Health of Disabled People Strategy and a New Zealand Health Strategy.

3.6.4 Standards, guidance, strategies and policies

This section describes key standards, guidance and strategies that have been developed in New Zealand, as well as monitoring bodies that assess compliance with these standards.

Standards

A number of standards have been developed to drive improvement and assess the quality of care provided to people living in New Zealand. This section sets out the standards specific to Needs Assessment Service Coordination (NASC) agencies and those delivering services to support people with disabilities, as well as other areas of health and social care. The following standards will be discussed:

- Social Sector Accreditation Standards Level 1 (2021)
- Ngā Paerewa Health and Disability Services Standard (NZS 8134:2021) (2021).

Social Sector Accreditation Standards Level 1 (2021)

The Social Sector Accreditation Standards (SSAS) for the accreditation of government-funded providers to deliver social services, were developed by Te Kāhui Kāhu, an independent government organisation, and have been used by them since 2016 to assess services.(215) The accreditation standards are a set of operating principles that organisations must follow to provide assurance that they can deliver safe, quality services to their community and government agencies.(215) There are four levels of accreditation, which are subdivided into four levels of compliance: reasonable, substantial, significant and highest level of compliance.(216)

Once an organisation applies for accreditation, Te Kāhui Kāhu carries out an accreditation assessment. This considers the capability of the organisation and the processes for the services it delivers.(200) Once accredited, the organisation is assessed regularly by a monitoring body to make sure they continue to meet the standards. An organisation’s accreditation level will determine how often assessments take place.

NASCs are audited against SSAS level 1 by the Standards and Monitoring Services (SAMS); a national organisation governed and primarily staffed by people and families with disabilities.(201) The outcomes from this monitoring are set out in Section 3.6.5. The level 1 standards are divided into 10 sections:

1. client-centred services
2. community well-being
3. cultural competence
4. staffing
5. health and safety
6. governance and management structure and systems
7. financial management and systems
8. resolution of complaints related to service provision

9. quality improvement
10. client services and programmes.(217)

Ngā Paerewa Health and Disability Services Standard (NZS 8134:2021) (2021)

The *Ngā Paerewa Health and Disability Services Standard* came into effect in early 2022.(218) The standard is applicable to a wide range of specialities, age groups and services, both public and private, within the health and disability sector, including providers of residential disability care. Services such as home and community support services who are not required to be certified under the Health and Disability (Services) Act 2001 are encouraged to adopt the standard as it promotes current best practice.(218,219) The standard is outcome focussed and reflects person-centred care, and is designed to empower people to make decisions about their own care and support in order to achieve their goals. A principles-based approach informed the standard. The five key principles are:

1. achieving Māori health equality
2. accessible health and disability services.
3. partners with choice and control.
4. best practice through collaboration.
5. standards that increase positive life outcomes.(218)

While the health and disability services standard is not directly applicable to NASCs, all services are encouraged to follow the principles of best practice. The standard provides the foundation for describing best practice and fostering continuous improvement in the quality of health and disability services. It sets out the rights of people and ensures service providers know their responsibilities for safe outcomes.

Guidance

In 2022, guidelines were developed to provide consistency and transparency of NASC processes across New Zealand. These guidelines aim to improve the quality of the service for people with disabilities and their families by increasing their choice and control. The guidance documents discussed in this section are:

- The Support Needs Assessment and Service Co-ordination Policy, Procedure and Information Reporting Guidelines (2022)
- Enabling Good Lives (EGL).

The Support Needs Assessment and Service Co-ordination Policy, Procedure and Information Reporting Guidelines (2022)

In 2002, the Ministry of Health (MOH) developed the Support Needs Assessment and Service Co-ordination Policy, Procedure and Information Reporting Guidelines. The guidelines were developed to address inconsistencies in NASC processes throughout the country and to ensure that NASC worked in line with government strategies.(198) The guidelines identify the policies and procedures that apply at each point of contact, for example when notifying the person on receipt of a referral and informing them of their rights. The guidelines outline the pathway through the system and specify minimum requirements in terms of the processes that should be followed, for example, what information needs to be recorded at the referral.

Enabling Good Lives (EGL)

Enabling Good Lives (EGL) is a foundation and framework to guide positive change for disabled people, families, communities and governance structures across New Zealand.(202) EGL is a partnership between the disability sector and government agencies aimed at long-term transformation of how people with disabilities and their families are supported to live their everyday lives. The vision and eight principles of the EGL approach are based on respect towards people with disabilities, whereby people with disabilities are trusted to be decision-makers in their own lives and to govern the resources used for their support. The vision of the EGL approach is:

> In the future, disabled children and adults and their families will have greater choice and control over their supports and lives, and make more use of natural and universally available supports.(220)

The eight principles of the EGL approach are:

- self-determination
- beginning early
- person-centred
- ordinary life outcomes
- mainstream first
- Mana (spiritual force) enhancing
- easy to use
- relationship building.(221)

The EGL principles underpin the NASC approach to needs assessment and service coordination for people with disabilities, adapting a positive strengths-based and whole life approach to the process.

Strategies and policies

The Support Needs Assessment and Service Co-ordination Policy, Procedure and Information Reporting Guidelines outlines NASCs requirement to align with the government’s strategies guiding service delivery, including the New Zealand Disability Strategy and the New Zealand Health Strategy.(198) In 2023, the Ministry of Health launched the government's Pae Ora, Healthy Futures Strategies required under the Pae Ora (Healthy Futures) Act 2022, this sets the direction for how all New Zealanders can live well and longer in good health.(222) This section sets out the following strategies;

- New Zealand Disability Strategy 2016 to 2026 (2016)
- The Provisional Health of Disabled People Strategy 2023
- The New Zealand Health Strategy 2023

New Zealand Disability Strategy 2016 to 2026 (2016)

Published in 2016, the aim of the New Zealand Disability Strategy was to guide the work of government agencies on disability issues from 2016 to 2026.(223) The Strategy set out an approach to ensure the disabled community in New Zealand is visible, acknowledged and respected on an equal basis with others, and that people with disabilities can live a life with dignity and feel valued.(224) The *Disability Action Plan 2019–2023* (2019) was developed in response to the main issues identified by people with disabilities, the Disabled People’s Organisation (DPO) Coalition and government agencies working together.(224) Priority areas for change include health and wellbeing, attitudes and choice and control.

Provisional Health of Disabled People Strategy (2023)

Published in 2023, the *Provisional Health of Disabled People Strategy* sets the direction and long-term priorities for the new health system to move towards achieving its vision of healthy futures for people with disabilities and their family.(225) The provisional strategy provides a framework to guide health organisations to improve the health outcomes for people with disabilities and their families over the next 10 years. The provisional strategy gives effect to Te Tiriti o Waitangi (the Treaty of Waitangi)[****] and is underpinned by the United Nations Convention on the

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[****] Te Tiriti o Waitangi is New Zealand’s founding document; the treaty is an agreement signed in 1840 between representatives of the British Crown and Māori chiefs.

Rights of Persons with Disabilities (UNCRPD). Five key priorities, including self-determination, access and determinants of health were developed through engagement with people with disabilities and their families, disability organisations and in consultation with government agencies, such as the Ministry of Disabled People.(225) The Health of Disabled People Strategy has been published in a provisional form to allow for further engagement with people with disabilities within the community and further shaping of priorities.

New Zealand Health Strategy 2023

The New Zealand Health Strategy 2023, part of a suite of strategies published under the Pae Ora (Healthy Futures) Act 2022, sets the direction for improving the health of all New Zealanders over the next ten years and sets a long-term vision focused on achieving healthy futures for all.(222,226) The strategy is founded on a commitment to the Treaty of Waitangi (Te Tiriti) and enacting the health system's obligations to Māori. The New Zealand Health Strategy's vision is underpinned by two long-term goals. These are:

- to achieve health equity for diverse communities, and especially for Māori, Pacific, disabled and other groups who currently have poorer outcomes
- to improve health outcomes for all New Zealanders.

3.6.5 Regulation, monitoring and inspection of assessment of need

Disability support providers contracted by the Ministry of Health are independently evaluated to ensure they are meeting contractual requirements to deliver quality supports and improved outcomes for people with disabilities. Monitoring and auditing of Needs Assessment Service Coordination (NASC) agencies is carried out by Standards and Monitoring Services (SAMS). This section outlines how SAMS monitor the NASCs to ensure they comply with:

- Enabling Good Lives (EGL)
- Social Sector Accreditation Standards (SSAS)

Enabling Good Lives (EGL)

NASCs are independently evaluated by the SAMS to ensure that they are meeting their contractual requirements and maintaining quality supports to people with disabilities. SAMS is a national organisation governed and primarily staffed by people and families with disabilities, committed to supporting positive change in the disability sector and wider community.(201)

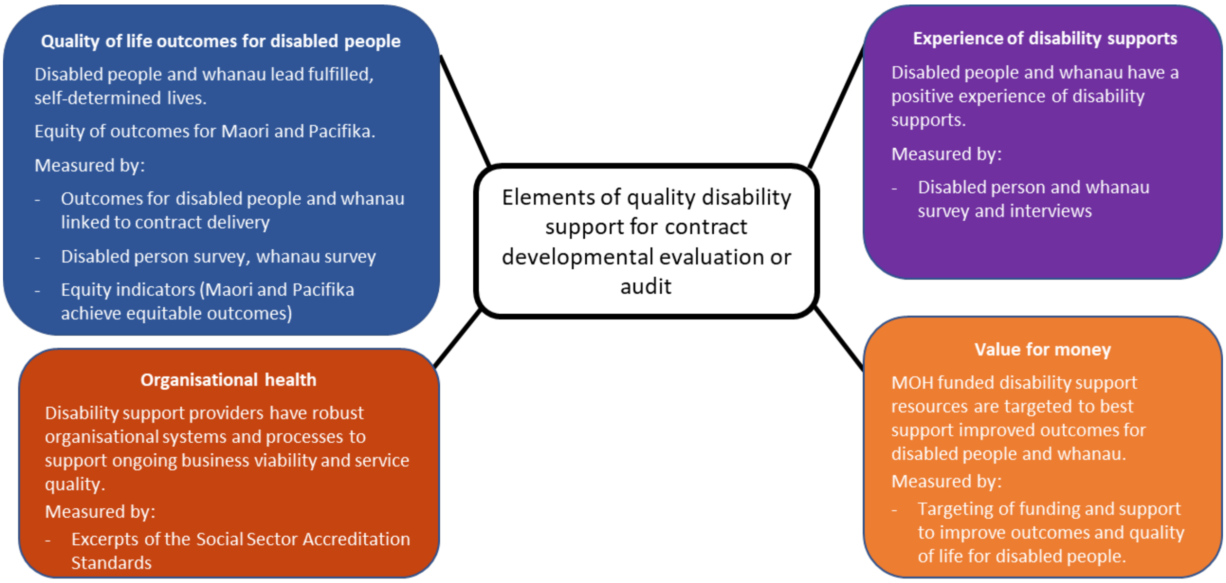
SAMS audit NASCs using the *Outcome Focussed Evaluation Tool for Needs Assessment and Service Coordination Services* (NASC); within this tool is a Enabling

Good Lives principles-based framework to ensure quality supports and improved outcomes for people with disabilities.(227) During an audit, NASCs are required to provide supports in accordance with key legislation, government strategies and standards, including and not limited to: the *New Zealand Disability Strategy 2016 to 2026, Social Sector Accreditation Standards Level 1* and the Enabling Good Lives Vision and Principles. There are four elements to the Enabling Good Lives Principles-based evaluation framework:

- quality of life outcomes
- organisational health
- experience of disability supports
- value for money.

The evaluation framework consists of high-level outcomes, indicators, and what the organisation should demonstrate in relation to the four elements.(227) The desired outcomes of these four elements and how they can be measured are summarised in Figure 5 below.

Figure 4. Four elements to An Enabling Good Lives Principles-based evaluation framework



Quality of life outcomes for disabled people

Disabled people and whanau lead fulfilled, self-determined lives.

Equity of outcomes for Maori and Pacifika.

Measured by:

- Outcomes for disabled people and whanau linked to contract delivery
- Disabled person survey, whanau survey
- Equity indicators (Maori and Pacifika achieve equitable outcomes)

Elements of quality disability support for contract developmental evaluation or audit

Experience of disability supports

Disabled people and whanau have a positive experience of disability supports.

Measured by:

- Disabled person and whanau survey and interviews

Organisational health

Disability support providers have robust organisational systems and processes to support ongoing business viability and service quality.

Measured by:

- Excerpts of the Social Sector Accreditation Standards

Value for money

MOH funded disability support resources are targeted to best support improved outcomes for disabled people and whanau.

Measured by:

- Targeting of funding and support to improve outcomes and quality of life for disabled people.

Source: Ministry of Health. *Outcome Focussed Evaluation Tool for Needs Assessment and Service Coordination Services* (NASC). (228)

Social Sector Accreditation Standards (SSAS)

A NASC is also assessed by SAMS to ensure they continue to meet the SSAS level 1 once accredited. If a NASC does not meet the standards, SAMS will advise on corrective actions in order to meet them. Accreditation can be suspended or removed from a NASC at any time by the Ministry of Health.(200)

3.6.6 Findings from reviews

In recent years, a number of reviews have been undertaken in relation to the health workforce of New Zealand. While there has been continuous growth in the health workforce over the past decade, it has not been sufficient to meet the population needs and growth.(203) In late 2022, the Ministry of Health (MOH) published the *Health Workforce Strategic Framework*, to guide health system settings and ensure New Zealand has a sustainable, representative and responsive health workforce that can meet future needs.(229) The framework was informed by engagements undertaken by the MOH with health workers and sector representatives from across New Zealand. The findings from the stakeholder engagement also informed the prioritisation of workforce initiatives in the *Health Workforce Plan 2023/24* published in 2023 by Health New Zealand and Maori Health Authority.(203) The plan identified a workforce that has not been developed or supported to the extent needed and a health workforce that is under strain. These gaps were driven by poor quality data, under-investments, fragmentation of the former district health boards and global workforce shortages.

In 2023, the *Disability Support Workforce, Community Engagement Summary* was published by the Ministry of Disabled People.(204) The report found that the disability support workforce landscape is complex and heavily impacted by staff shortages affecting the entire health workforce. The report highlighted that while there is a range of strategic initiatives in place which address parts of the workforce, there is not a sector-wide cohesive or joined-up approach. The report also found that the disability sector is experiencing significant transformation with the implementation of Enabling Good Lives and requires further support to enable a successful system change.(204) Key challenges highlighted in the report included barriers to recruiting people into the disability workforce, gaps in training programmes and issues with retention across the sector, particularly amongst workers with more specialised skills and training.

While Needs Assessment Service Coordination (NASC) agencies are not experiencing delays in relation to facilitating needs assessments and statutory timeframes are being met, the current workforce challenges are impacting on the NASCs ability to provide service coordination.[††††] The inability of services to meet current demand has resulted in insufficient supports to address the growing need for services. For example, there are no defined Autism Spectrum Disorder (ASD) services to refer to, despite ASD referrals accounting for 40% of the total referrals. Resourcing is

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[††††] This information was provided by subject matter experts from Needs Assessment and Service Coordination New Zealand interviewed on 22 January 2024 to inform this research report.

reported to be is an issue across all areas. (6) With extremely remote areas in New Zealand, this can add to the challenge of providing adequate services to these areas and the people who live there.

3.6.7 Key Findings

Children with disabilities in New Zealand have a right to a needs assessment in order to avail of publicly-funded disability support services. Needs Assessment Service Coordination (NASC) agencies are responsible for needs assessment and service coordination. During the assessment, a person's abilities, resources, goals and needs are considered. The purpose of the assessment is to decide what is needed to maximise a person's independence. The assessment is underpinned by the Enabling Good Lives (EGL) principles. Following an assessment, service planning and service coordination is undertaken. An assessment of special educational needs is not included in the assessment, this is a separate process under the Ministry of Education.

The approach to assessment of need has changed in recent years and there are a number of lessons to be learned for Ireland from this reform. Historically, the needs assessment to determine disability supports was a deficit-based assessment, this has now moved to a strengths-based approach underpinned by the principles of the EGL initiative.(221) The assessment asks what a good life looks like for the person assessed and takes a holistic, person-centred approach with a focus on the child's abilities, resources, goals and needs.

Service planning and service coordination are undertaken only after the needs assessment has been completed and the needs of the person have been identified. This ensures services are planned on the individual's needs and not based on the availability of resources.(209) NASCs have a clear separation in their structure between the functions of facilitating assessment of need and service co-ordination. This separation between functions is of interest, as the purpose is to remain objective and transparent in identifying the needs of the person irrespective of resource availability.

In order to deliver needs assessment and service coordination, NASCs receive funding from the Ministry of Health (MOH), the Ministry of Disabled People and the Accident Compensation Corporation (ACC).(210) Budgets are agreed between NASCs and the appropriate funding body based on population data and caseload, however this siloed model of funding is problematic. Complexities exist around the criteria that are in place to determine what funding and supports people get from the various funding bodies. It is notable that the EGL approach outlines objectives in relation to funding; these include a system where there is one pool of state funding, that is, that all government agencies put funds into one 'bucket' as well as providing individuals and families with more choice and control over how they manage their funding themselves.(202)

In general, the statutory timeframes for needs assessments are being met, however, challenges and delays are reported in service coordination due to insufficient government funding, a lack of available services and workforce related challenges. Services are unable to meet the demand and this has created waiting lists for services. As a result, the system is becoming more contested and more legal challenges are arising as further delays to accessing services are experienced. Challenges also exist in facilitating service coordination and adequate supports to people living in extremely remote areas throughout the country.

Children with Special Educational Needs (SEN) are not under the remit of NASCs. Engagements with subject matter experts in New Zealand found that this creates issues for children with SEN and those with low to moderate needs. The Ministry of Education is responsible for providing support and access to education, but the service provided is reported to be inadequate, due to a lack of funding and resources, leaving children waiting for services and without the supports they need.(230)

The monitoring body for NASCs is the Standards and Monitoring Services (SAMS).(201) Rather than an auditing agency, SAMS is described as ‘a national evaluation, education and leadership development organisation’. What sets SAMS apart from other auditing agencies is that it is governed and primarily staffed by people and families with disabilities. In auditing the NASCs, SAMS provide support and advise corrective actions to assist NASCs achieve and maintain the EGL principles.

3.7 Iceland

This section describes the organisation and delivery of assessment of need in Iceland. The section is set out under the following headings:

- overview of assessment of need
- the model of service
- relevant legislation
- standards, guidance, frameworks, strategies and policies
- regulation, monitoring and inspection of assessment of need
- findings from reviews
- key findings.

3.7.1 Overview of assessment of need

In Iceland, people with disabilities have a statutory entitlement to receive early support, intervention and diagnosis; legislation sets out the right of people with disabilities to receive support based on their needs regardless of diagnosis, or even if there is no diagnosis.(231,232) Legislation in Iceland sets out the role and functions of the state run Counselling and Diagnostic Centre (RGR) responsible for facilitating needs assessment, and the requirement for integrated services.(231,233) The population of Iceland in 2024 is reported to be 383,726 people.(234) In 2017, about 8,900 people, or 4.0% of the population, stated that they had a disability.(234) There were no statistics found on the number of children with disabilities in Iceland.

The 64 municipalities of Iceland are the local administrative areas responsible for initial observations and developmental assessments carried out to identify developmental delays and disorders in children from an early age.(235) When a child is believed to have a serious developmental disorder, a referral to the RGR is required for a diagnostic assessment.

All assessments of need for children in Iceland are focused on early intervention and prevention, and emphasis is placed on immediate and targeted interventions. Multidisciplinary teams conduct the assessment and review the medical and social development of the child as part of this process.(236) The assessment is based on family-oriented services, with an emphasis on the participation of parents and the service providers connected to the families, such as schools, social services and school services.(237)

In terms of the oversight of assessment of need in Iceland, there are no standards for assessment of need and at the time of writing, and no government strategies or policies related to the disability sector. Currently, there is no monitoring of assessment of need in Iceland. In 2019, an academic review of the disability assessment in Iceland found that the assessment method is considered a ‘gold standard’ in diagnosing autism spectrum disorder (ASD) on an international level (consistent with International Classification of Diseases, Tenth Revision (ICD-10) or Diagnostic and Statistical Manual of Mental Illnesses (DSM-5) criteria)(238).

3.7.2 The model of service

In Iceland, responsibility for the initial assessment of children with developmental delays or disorders and the delivery of services to children with disabilities lies with the municipalities. The state-run organisation, Counselling and Diagnostic Centre (RGR), is responsible for the assessment and diagnosis of children with severe developmental disabilities. This section sets out the model of service under the following headings:

- structure and governance of assessment of need
- scope of assessment of need
- assessment of need process
- appeals process.

Structure and governance of assessment of need

Municipalities are responsible for the initial assessment of a child’s needs, conducted in the child's immediate environment by specialist services in preschools or primary schools, specialist healthcare services or self-employed experts. The municipalities are responsible for early intervention in preschools and for the organisation and provision of services for people with disabilities, including the quality of the service, whether it is provided by the municipality or by private providers.

If a child is identified as having more complex needs, a referral is made by relevant health, social care or education services to the RGR. The RGR is under the remit and funding of the Ministry of Education and Children; prior to 2022 it was under the Ministry of Social Affairs and Labour. The RGR has a legislative remit to serve children and adolescents from birth to 18 year olds and their families throughout the country.(237) The RGR aim to help children with developmental disabilities achieve their potential and enjoy success in adult life by providing:

- early intervention
- multidisciplinary assessment

- counselling
- access to resources.(239)

The RGR is also obliged to educate parents and professionals about children's disabilities and main treatment methods.(239)

Scope of assessment of need

RGR is intended to serve children with serious developmental disorders which may lead to disability in the future. The Act on Services for Disabled People with Long-Term Support Needs (no. 38/2018) contains a detailed definition of disability which is:

> The result of impairments and obstacles of various kinds that arise from the interaction of people with impairments and the environment and attitudes that prevent full and effective social participation on an equal footing with others. The impairments of the person concerned are long-term and the barriers are such that the person is discriminated against because of a physical, mental or intellectual impairment or impaired perception.(239)

The Act on Counselling and Analysis Centre no. 83/2003 defines disability as:

> The condition that arises when a person needs multifaceted services and long-term assistance due to a serious developmental disorder or other impairment of skills.(240)

RGR serve children of preschool age (from birth to five year-olds) and primary and secondary school age (six year-olds and up) and their families with severe developmental disorders referred for consideration after initial diagnosis. A review of the child's educational needs and their status at school is included in assessments conducted by the municipalities and the RGR.

Assessment of need process

This section outlines the various processes in assessing the needs of children with disabilities in Iceland, at local level by the municipalities and by the RGR. The steps include:

- initial assessment
- diagnostic assessment
- long-term follow-up.

Initial assessment

When a delay in a child's development or adjustment is suspected, families or guardians of the child consult a professional who knows the child and seek advice on the necessary examinations. In the case of infants, advice is provided from specialists who care for the infant, a paediatrician or a primary care physician. In terms of preschool or primary school children, first observations and assessments are conducted in the child's immediate environment by the speech and language therapists and or clinical psychologists within the school services. Alternatively, they are undertaken by healthcare professionals such as paediatricians. If no serious developmental disorders are identified, services are provided to the child and their families at local level by the municipalities.

The RGR provide the municipalities with guidelines, operating rules and codes of practice for the initial assessment and information gathering process. This information includes:

- health and development history
- family circumstances, for example siblings, health status, parents' circumstances
- social inclusion and integration
- educational status in the case of a child of primary school age
- cognitive development with an approved developmental test
- behaviour and wellbeing gathered through questionnaires from parents, teachers and other caregivers
- results of any treatment where a child has been in specialised observation and intervention outside the home and school
- previous observations.(241)

Information is gathered through interviews with parents and the child, as well as standard observations and questionnaires. Teachers provide important information about the child’s learning, skills, and social status at school. Professionals in other services such as allied health and social care services provide information as required.(241) If a more serious developmental disorder is identified during the initial assessment which may lead to a disability in the future, a referral is made to the RGR in order to receive a diagnosis, counselling and other resources aimed at reducing the consequences of the disorder.(240) It is the responsibility of the specialist who carried out the examinations to formally refer the child to RGR. It is also their responsibility to recommend that appropriate services, training and special education begin as soon as possible.(242) There are no statutory timeframes for conducting an initial assessment or referral to the RGR.

Diagnostic assessment

A referral to the RGR can only be made through a specialist after they have conducted an initial assessment, parents or guardians acting on behalf of a child cannot apply directly to the RGR for a diagnostic assessment. In the case of a serious congenital problem, a child is often referred to the RGR soon after birth or directly from the maternity or paediatric department. Children up to the age of two years are provided intervention or counselling quickly after referral. The largest group referred to the RGR is preschool age, two to five year-olds; the most common reasons for referrals is Autism Spectrum Disorder (ASD). The next largest group of referrals is the six to 18 year-olds, referred for assessment for intellectual disability.(242)

Referrals to the RGR are triaged on receipt due to the high volumes received; cases are prioritised for assessment based on the severity of the disability. A psychologist reviews the referrals and undertakes initial testing to inform the nature of each assessment. Multidisciplinary teams conduct the assessment and review the medical and social development of the child, for example an ASD assessment requires health and social care professionals, usually a paediatrician, a clinical psychologist and a social worker.(236) During the assessment process, emphasis is placed on identifying how to promote independence and participation in society. International screening and diagnostic tools, for example International Classification of Diseases, Tenth Revision (ICD-10) are followed.

Generally, a child and their family will attend the RGR for an assessment. However, as Iceland has a small population with many remote areas, if a number of assessments are due in one area, or families live in extremely remote areas, assessors may travel to provide assessments and advice locally. Additional, funding is being sought to expand this mobile service.

While waiting for an assessment to be completed, the RGR will commence interventions, providing the child and their family with counselling and advice based on the child needs, and allocating supports such as an autism spectrum disorder (ASD) advisor or an intellectual disability specialist. This ensures that the child is in receipt of services that meet the needs set out in the initial referral, in line with legislative requirements.(233)

When the RGR receive a referral for children aged three to six years old, the child is generally appointed an adviser. The advisor contacts the family and the local service provider or case manager and attends meetings about the child as required, for example at the child’s preschool.

During an assessment for an older child, a professional, for example a clinical psychologist is selected to become a link person. The link person engages with parents to establish the needs and strengths of the child and family and provide support. The link person also shares information with other professionals including the advisor, if allocated. This link person evaluates what assessment tools, questionnaires and other tools to use in relation to the diagnostic assessment; this role of a link person may vary depending on the nature of the issues and procedures in the professional areas.(243)

Following an assessment, the RGR provides a diagnosis for the child and compiles a service plan with recommendations as to what interventions and supports are needed. A coordinator or case manager in the municipalities, for example in the school or in social services, has responsibility for coordinating support services and the integration of services for the family.(233)

There are no statutory timeframes for assessments conducted by the RGR. Currently, the RGR are experiencing long waiting lists, with some children waiting 18 months to two years for an assessment[‡‡‡‡] The number of referrals to the RGR has risen, in 2023 the RGR recorded the highest number of referrals. This can be attributed partly to an increase in the Icelandic population and amendments to the Act on Counselling and Diagnostic Centre, and is discussed further in Section 3.7.3.

Long-term follow-up

The long term follow-up department within the RGR serves children and adolescents aged from two to 18 years old who may need specialised services for a long period of time. This can include children with developmental disorders and behavioural or communication problems, such as children with moderate to severe intellectual disability, and children with ASD with significant impairments. The long term follow-up department is made up of health professionals such as paediatricians, behaviourists, physiotherapists, occupational therapists, social workers, developmental therapists and speech pathologist who carry out investigations. The department's services are multidisciplinary and take into account the needs of children and their families. This department also provides education and counselling to families and partners, both in the form of individualised education and courses. Among the services provided by the department are follow up and counselling on behaviour, wellbeing, assistive devices, communication, various rare diseases and syndromes.(244)

The long term follow-up department monitors the skills and progress of the child’s disability over time.(244) The team at local level meet regularly to discuss the

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[‡‡‡‡] This information was provided by subject matter experts from Ráðgjafar-og greiningarstöð Iceland, interviewed on 06 March 2024 to inform this research report.

wellbeing of the child and family, progress in education and social status. Advisors from the RGR may attend these meetings if close monitoring of specialised recommendations is required. The majority of cases under long term follow-up will be reviewed annually, however some cases may require a review every six months based on the child's needs.

In order to ensure a targeted and fair distribution of the resources provided by the state for services to children and adults with disabilities, the RGR also conduct a standard assessment of the extent of support needs.(245) This assessment is carried out at local level by independent experts using the assessment system Supports Intensity Scale Children's Version, (SIS-C) for children. The aim of this SIS-C is to inform the allocation of funds from the Municipal Equalization Fund[§§§§] and to make individual plans for support.

Appeals process

If parents or guardians are unhappy with the diagnosis they receive, they can contact the RGR to discuss this. Formal complaints can be made directly to the RGR. There is also a formal appeal process available through the Welfare Quality and Inspection Authority (GEV) website. GEV monitors the quality of various social services. GEV receives and processes notifications of service failures from family members and others, complaints from people using services and notifications of serious unexpected events from service providers.(246) If families are not satisfied with the service or the supports they are receiving from the municipality, they can submit a complaint to the municipality.

3.7.3 Relevant legislation

The requirement for children to receive early support and intervention based on their needs regardless of a diagnosis is set out in Icelandic legislation. Legislation also stipulates the role of the Counselling and Diagnostic Centre (RGR) in providing assessments and services to children with disabilities and developmental disorders. This section outlines key legislation as follows:

- Act on Counselling and Diagnostic Centre No.83/2003
- Act on Services for Disabled People with Long-Term Support Needs No. 38/2018
- Act on the Integration of Services in the Interest of Children's Prosperity, No 86/2021.

[§§§§] The Municipal Equalization Fund was established to incentivise a new fiscal operating model between the central and municipal governments.

Act on Counselling and Diagnostic Centre No.83/2003

The Act on Counselling and Diagnostic Centre was first entered into force in June 2003 with amendments enacted in 2022.(240) The 2022 amendment to this Act transferred the RGR from the Ministry of Social Affairs to the Ministry of Education and Children and placed a heightened focus on early intervention and integration for all children in need of additional support.

The purpose of this Act is to ensure that children with serious developmental disorders which may lead to disability receive a diagnosis, counselling and other supports aimed at reducing the impact of the disorder. The Act sets out the role and responsibility of the RGR to serve the entire country using a multifaceted and family-oriented approach with an emphasis on early intervention.(240)

Act on Services for Disabled People with Long-Term Support Needs No. 38/2018

The aim of the Act on Services for Disabled People with Long-Term Support Needs is to provide people with disabilities with the best services that can be provided at any given time to meet their specific support needs.(232) The Act specifies the right for people with disabilities to receive early support, intervention and diagnosis. The Act states that an initial diagnosis and or other assessment of a child's needs must be carried out as soon as possible, but that the child's support needs must be met even if there is no diagnosis.

The Act sets out the rules and responsibilities of state institutions and the municipalities responsible for the organisation and implementation of services for people with disabilities. The Act also sets out the entitlements of children with disabilities including:

- individual service plans and service teams
- the necessary services so that children with disabilities can enjoy their human rights
- early support, intervention and assessments
- short-term stays outside the home.(232)

Under the Act, service providers and providers of general services for the wellbeing of children have an obligation to respond to indications that a child's needs are not being met. If a service provider considers that a child has support needs due to a disability that are not being met, and if the parents of the child choose not to seek support, the service provider is obliged to gather information and evidence on the child's situation and communicate this to the relevant department within the municipality.

Act on the Integration of Services in the Interest of Children's Prosperity, No 86/2021

In 2022, the Act on the Integration of Services in the Interest of Children's Prosperity was entered into force and the Ministry of Education and Children holds responsibility for the Act.(233) The principle aim of the Act is for children and parents in need to have access to suitable integrated services without impediment. The Act sets out the responsibility of services to monitor the welfare and prosperity of children and evaluate their need for services, to respond effectively to children's need for services, and to consult among themselves, with the aim of providing continuous and integrated services.

The Act stipulates the requirements for all children and parents to have access to a coordinator of services within the municipality. The role of the coordinator is to provide information about services, assist with ensuring access to an initial assessment of needs and to organise and follow up on the integration of primary level services provided by the municipalities. Where a child is in need of services at the secondary and or tertiary level, the municipality appoint a case manager of services.(233) The implementation phase of the Act is three to five years.

3.7.4 Standards, guidance, frameworks, strategies and policies

As noted, there are no standards for the assessment of needs or for the disability sector more broadly in Iceland, nor is there any guidance, strategies or policies in relation to assessment of need or disability in place. However, the Welfare Quality and Inspection Authority (GEV) who have responsibility for monitoring the quality of social services, have developed quality criteria for social services for people with disabilities. The quality criteria explain what people with disabilities should expect from social services. The quality criteria are based on Icelandic law and human rights agreements, such as the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). The quality criteria provide a useful benchmark for people who use services, for service providers and for regulators to evaluate whether the service is adequate.(247) The four quality criteria are:

1. The service enables me to live an independent life.
2. I am involved in shaping the service I receive.
3. I have confidence in those who provide me with services.
4. The service I receive is safe and reliable.(247)

Quality indicators in the form of outcome statements help people with disabilities describe what they think the service is like. Children and adults can use these quality indicators to review the services they receive.(247) The quality indicators include a number of statements under the headings below:

1. I can live an independent life with the services I receive.
2. I am involved in deciding what kind of service I receive.
3. I trust people who provide me with services.
4. I can count on the service I receive.

The quality indicators were prepared in close cooperation with the key stakeholders, including the Counselling and Diagnostic Centre (RGR).(247)

3.7.5 Regulation, monitoring and inspection of assessment of need

While there is no specific monitoring or inspection of assessment of need in Iceland, the Welfare Quality and Inspection Authority (GEV) is responsible for monitoring the quality of social services that provide supports to people with disabilities. GEV was established in 2022 and while independent in its work, it is under the authority of the Ministry of Social Affairs.(246) GEV seeks to improve quality and safety of services and ensure that services are provided in accordance with law and international treaties. The main tasks of GEV are to develop quality criteria, grant individual licences to social services, monitor compliance of these licences, monitor the quality of services and receive and process complaints from service users.(248)

3.7.6 Findings from reviews

In 2019, the Academic Network of European Disability Experts (ANED) published a country report on disability assessment in Iceland.(238) The report outlines the type of disability assessment in Iceland and provides case studies and examples of how assessments are undertaken. The report reviewed the process used by RGR in the assessment for children and young people with Autism Spectrum Disorder (ASD). The report found that the assessment method is considered a ‘gold standard’ in diagnosing ASD on an international level (consistent with International Classification of Diseases, Tenth Revision (ICD-10) or Diagnostic and Statistical Manual of Mental Illnesses (DSM-5) criteria). The report highlighted that some stakeholders suggested that the assessment could be improved, with more emphasis being placed on the needs and preferences of each child and the family, strengths within the child and the family, as well as on the environment, as this highly affects each child’s functioning and wellbeing. The report noted that diagnosis could be a more dynamic process and should include more social elements.(238)

3.7.7 Key findings

In Iceland, legislation stipulates that a child's support needs must be met, even in the absence of a formal diagnosis and that the child and family must have access to suitable integrated services.(232,233) Assessment of need includes initial and diagnostic assessments; these assessments are based on a programme of early invention and prevention, to identify developmental delays and disorders at an early stage and start interventions immediately. The municipalities hold responsibility for the initial assessments carried out in the child's environment and the delivery of services, while the centralised Counselling and Diagnostic Centre (RGR) is responsible for the diagnostic assessment for those believed to have more serious development disorders. There are no standards for assessment of need in Iceland. An assessment of special educational needs is part of the assessment process.

There are a number of lessons for Ireland that can be drawn from Iceland. Amendments to legislation in Iceland have placed additional focus on early intervention and prevention in relation to addressing the needs of children with disabilities. Initial assessments for children believed to have a disability are carried out in the child's immediate environment by specialists that know and work with the child, for example in the child's preschool or primary school. The municipalities are responsible for conducting the initial observations and assessments, and for the organisation and provision of services. Only if a child is believed to have a severe disability are they referred to the RGR for a further assessment. This early intervention aims to positively impact the children's developmental progress. Identifying development disorders early allows the municipalities to provide interventions immediately to meet the child's needs, reducing the escalation of more serious developmental disorders which may lead to a disability in the future.

The RGR's work is based on a family-centred service in collaboration with families, other professionals, and cross-sectional teamwork. In conducting a diagnostic assessment, the RGR work with the specialists in the child's environment, such as school services and the child's family to gather information about the child's medical and social development. Professionals working with the child in their environment are consulted to inform the child's assessment and to ensure a holistic, person-centred approach.

The assessment at the RGR is multifaceted. On receipt of a referral from the municipalities, the RGR conduct a diagnostic assessment and provide advice and counselling to the child and family. Based on the comprehensive referral from specialists in the municipalities, interventions commence immediately to meet the identified needs of the child. Following an assessment, the RGR provide a diagnosis for the child and compile a service plan with recommendations as to what interventions and supports are needed; they also provide education and counselling to families during the assessment process. The child is supported through the whole process from the initial assessment to the receipt of services.

Some children in Iceland are experiencing long waiting lists for diagnostic assessments, in some cases up to two years. While awaiting assessments however, children and families are provided advice, counselling and services based on the disability. Notable for Ireland is legislation that stipulates that children receive the supports required to meet their individual needs regardless of, or in the absence of a diagnosis. This early invention ensures that children are not left waiting for supports they need and their progress is not delayed.

3.8 Romania

This section describes the organisation and delivery of assessment of need in Romania, and the effectiveness of these services. This section is set out under the following headings:

- overview of assessment of need
- the model of service
- relevant legislation
- standards, guidance, frameworks, strategies and policies
- regulation, monitoring and inspection of assessment of need
- findings from reviews
- key findings.

3.8.1 Overview of assessment of need

In Romania, people with disabilities have a statutory entitlement to avail of social benefits or services designed to support people with disabilities, and the disability assessment required in order to qualify for these services. Legislation sets out the role and organisation of the Complex Evaluation Service and the Child Protection Commission (CPC) within the General Directorate for Social Assistance and Child Protection (DGASPC).(249,250) Legislation also provides the biopsychosocial***** criteria for classifying children with disabilities and the method and algorithm used to calculate the level of disability.(251) The population of Romania in 2024 is reported to be 19.6 million people.(252) In 2020, the total number of people with disabilities was over 857,638 persons, approximately 4.4%.(253)

The DGASPC at local level, is responsible for the disability assessments of children and adults to determine the type and level of their disability.(254) The Complex Evaluation Service within the DGASPC, conducts disability assessments for children.(255) The assessment for children entails a review of medical evidence, combined with an assessment of their abilities and biopsychosocial criteria.(251) The assessment is focused on function, integration, and the participation of the child in the community.

While Romania does not have standards specific to assessment of need, they have developed mandatory minimum standards for case management for organisations

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***** The biopsychosocial approach considers biological, psychological, and social factors and their complex interactions in understanding health, illness, and health care delivery.

working in child welfare. The Complex Evaluation Service within the DGASPC is monitored against these standards and relevant legislation as outlined in Section 3.8.5. The launch of the *National Strategy for the Rights of Persons with Disabilities 'An equitable Romania', 2022-2027* with specific objectives, targets and measurable indicators, is Romania's first strategy on the topic of disability inclusion.(253,256) A recent report indicated that following the ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2010, alignment to the convention has been slow in terms of service provisions and the rights of people with disabilities.(256) Recent reviews of the disability assessment process also highlighted a lack of information available to people with disabilities, a complex application process and that in practice, a medical model is largely followed in assessments.(253,257)

3.8.2 The model of service

In Romania, responsibility for the delivery and organisation of assessment of need lies with General Directorate for Social Assistance and Child Protection (DGASPC). This section sets out the model of service under the following headings:

- structure and governance of assessment of need
- scope of assessment of need
- assessment of need process
- appeals process.

Structure and governance of assessment of need

DGASPC is a public body, established in 2004 under the remit of the county councils.(258) The DGASPC is funded from both state and county budgets and provides assistance and supports for people through 47 services within the counties and the municipality of Bucharest. Each local DGASPC operates a number of directorates, including a Child Protection Directorate which is focused on specialised intervention and the development of services to assist and protect children in need; they also provide family services including a Complex Evaluation Service.

The Complex Evaluation Service provided to children has a statutory duty to conduct disability assessments and support children with disabilities and learning difficulties to access support services.(259) The Child Protection Commission (CPC) is a specialised body that sits within the county councils that is responsible for special protection measures for children. Their role includes determining the classification of children with a disability grade, issuing the disability certificate and approving the proposed 'habilitation-rehabilitation plan'.(250) The National Authority for the Protection of Child Rights and Adoption (ANPDC) is a government body whose aim is to protect and promote the rights of children in Romania.(260) ANPDC develops guidance and work procedures for services providing supports to children to ensure that their rights are respected.

Scope of assessment of need

Any Romanian citizen, a person from another country or a person without citizenship who resides in Romania may apply for a disability assessment and obtain a disability certificate, if they meet eligibility criteria set out in Law no. 448/2006.(254) Both children and adults can apply for a disability assessment in order to access support services for people with disabilities. There are ten types of disability according to Romanian legislation: physical, visual, auditory, deaf and blind, somatic, mental, psychological, HIV or AIDS, associated (two or more disabilities) and rare diseases.(254)

While education forms part of the assessment criteria for the disability assessment, a child's special educational needs are evaluated and organised by the Ministry of National Education and Scientific Research.

Assessment of need process

Anyone can apply for a disability assessment in Romania, an application can be submitted to the registry of the DGASPC or to the registry of the town hall where the person resides.(254) The Complex Evaluation Service for children with disabilities within the DGASPC follows the below process:

- identifies children with disabilities and learning difficulties who require a disability assessment through direct requests, referrals from professionals working with the child or official notifications
- reviews and verifies applications for an assessment
- conducts a complex assessment of the child at their home in exceptional circumstances
- drafts a complex evaluation report for each child
- drafts an individual programme of support for each child, known as a habilitation-rehabilitation plan
- recommends a classification of the type and level of disability to the Child Protection Commission
- supports the child and monitors the implementation of the support plan

- notifies the parents or legal representative of the date set for the reassessment of the child.(259)

Assessments for children with disabilities are carried out with a combination of documentary evidence and personal interaction. Supporting evidence such as a self-assessment (statement or structured questionnaire completed by the individual) or a medical letter from a doctor may be provided.(258) When submitting an application on behalf of a child, applicants are required to provide a wide range of documents including:

- a medical certificate issued by the relevant health organisation and a medical letter from a specialist doctor
- a completed psychological evaluation form, if applicable, issued by a certified psychologist
- identity cards for the child and the parents or legal representatives
- the child's birth certificate
- the parents' marriage certificate, or death certificate if applicable
- a student certificate and a completed psycho-pedagogical evaluation form
- documents certifying the legal status of the child, for example divorce and custody rights, adoption or guardianship decisions
- medical documents detailing the child's condition and medical history, for example hospitalisations, health records, CT scans, ultrasounds, audiograms
- income certificates for both parents or legal representatives
- housing documents
- a medical form completed by the child's family doctor
- a school orientation certificate, if applicable
- a certificate issued by a support worker assisting the child, detailing the type, period and the frequency of therapy sessions.(259)

The disability assessment for children is carried out in two phases. In the first phase, a specialist selected by the child's parents or guardians conducts a multi-disciplinary assessment which includes medical, psychological, social and education evaluations, this is mandatory for the development of habilitation-rehabilitation plan. This assessment is organised by the child's parents or legal representatives and then submitted to the local DGASPC.(254) On receipt of an application to the DGASPC, a case manager within the Complex Evaluation Service opens the case and assigns it to the relevant professionals. A case manager is assigned to each child and remains with the child throughout the process and for the duration of the disability certificate issued. The case manager makes contact with the person within five working days to advise a date to attend for an assessment in the DGASPC where the person resides. The assessment can also be carried out at home if, for medical reasons, the person cannot attend.(254)

An assessment is required to take place within 60 days of receipt of the application.(254) The team conducting the assessment comprises of a doctor (preferably a paediatrician), a psychologist, an education specialist and a social worker. The doctor and psychologist review the medical criteria based on the documentation submitted and the interaction with the child. Social and psychosocial criteria are reviewed by all members based on International Classification of Functioning, Disability and Health, version for children and young people (ICF-CT) developed by the World Health Organisation (WHO).(251,261) Following the assessment, a complex evaluation report containing recommendations for classification or non-classification and the proposed Individual Program for Rehabilitation and Social Integration (PIRIS) is drafted.

In the second phase of the assessment, the child's type of disability and level of impairment is identified based on the assessment; the four levels of impairment are: light, medium, accentuated or severe. The level of disability is calculated by applying the assessed biopsychosocial criteria to an algorithm as set out in Order no. 1306/1883/2016. The PIRIS report is analysed by the CPC at county level who provides a decision on the assessment outcome within 15 working days from the date of referral and issues the disability certificate for the child accordingly.(254) The child and their parents are involved at each step of the process and the parents must approve the report. If the CPC does not approve the type or level of disability recommended within the report, the assessment is reviewed. The validity period of a certificate granted to a child is dependent on a number of factors, including their impairments, activity limitations and participation restrictions. The certificate can be granted for a minimum of six months to a maximum of two years. A child's case manager will monitor the implementation of the support plan for the duration of the certificate. A review of the plan is conducted annually and a report drafted. Without a disability certificate, a person is not entitled to any social benefits or support services designed for people with disabilities.

Education forms part of the assessment criteria for the disability assessment, as outlined in Order No 1985/1305/5805/2016.(262) Following a disability assessment at the DGASPC, an internal evaluation commission will evaluate the child's needs. The internal evaluation commission and the CPC can recommend the child attend special education. Members of the internal evaluation commission include health and social care professionals working in special education. A child's special educational needs are organised by the Ministry of National Education and Scientific Research.

Appeals process

An applicant has 30 days from the date of issue to contest a certificate. Since May 2023, appeals can be submitted by email or directly to the Child Protection Commission (CPC) that issued the certificate. Alternatively, appeals can also be submitted to the National Authority for the Protection of the Rights of Persons with Disabilities (ANPDPD).

3.8.3 Relevant legislation

This section outlines the legislation that applies to the disability assessment and the disability certificate issued to children and adults with disabilities in Romania. The key legislation, Law no. 448/2006, regulates the rights of people with disabilities to benefit from social assistance, health protection (prevention, treatment and recovery services), professional education and training supports to enhance social integration and inclusion within society.(249) The law also sets out the requirements and obligations of local authorities in providing the disability assessment. The legislation covered in this section includes:

- Law no. 448/2006 on the Protection and Promotion of the Rights of Disabled Persons in Romania (2006)
- Order of the Ministry of Health and Ministry of Labour, Family, Social Protection and the Elderly no. 1306/1883/2016 (2016)
- Decision no. 502/2017 on the organisation and functioning of the Child Protection Commission (2017).

Law no. 448/2006 on the Protection and Promotion of the Rights of Disabled Persons in Romania (2006)

Law no. 448/2006 sets out the rights of people with disabilities in accessing and benefiting from social services and supports following a disability assessment.(249) The law outlines the types of social services that people with disabilities have a right to access, and the roles and responsibilities of the county councils in providing and funding these services. It sets out the criteria in determining a person's type and level of disability, the medical and psychosocial evaluations of the assessment, the ten types of disabilities and the four levels of disability (art. 86).(249) By law, the county councils are obliged to provide access to supports according to the disability assessment outcome and the disability certificate issued to a person (art. 85). The law also stipulates the role and responsibility of the Complex Evaluation Service and the Child Protection Commission (CPC) for providing the disability assessment to adults and children and their legal duties (art. 86 and 87).

Order of the Ministry of Health and Ministry of Labour, Family, Social Protection and the Elderly no. 1306/1883/2016

Order no. 1306/1883/2016 sets out the biopsychosocial criteria for classifying children with disabilities and the method and algorithm used to calculate the level of disability.(251) According to article two of this order, the biopsychosocial criteria are divided into two categories: medical and medical-psychological criteria, and social and psychosocial criteria. The order also specifies the use of the International Classification of Functioning, Disability and Health, version for children and young people (ICF-CT) in assessing psychosocial criteria.

Under this order, the General Directorate for Social Assistance and Child Protection (DGASPC) are responsible for applying the biopsychosocial criteria to the disability assessment to calculate the level of disability. By assessing and applying the medical and psychological criteria and the social and psychosocial criteria, a figure is reached which represents the estimated percentage of the person’s functional impairment.(251)

Decision no. 502/2017 on the organisation and functioning of the Child Protection Commission (2017)

The Decision no. 502/2017 on the organisation and functioning of the CPC, sets out amendments to previous laws related to the protection and promotion of the rights of the child.(250) The decision sets out the structure and the organisation of the CPC, including the members required to sit on the commission. The decision also outlines the roles of the CPC, their requirement to make decisions on the disability assessment and the level of disability, how those decisions are made and the requirement for them to issue the certificate of disability.

3.8.4 Standards, guidance, frameworks, strategies and policies

Romania has no specific guidance, frameworks or policies developed in relation to assessment of need. While Romania does not have standards specific to assessment of need, they have developed *Mandatory Minimum Standards on Case Management in the Child Welfare Sector*.(263) A recent *National Strategy for the Rights of Persons with Disabilities ‘An equitable Romania, 2022-2027’* sets out the direction for change for services working with people with disabilities in Romania.(253) This section provides further detail on standards and strategies relating to assessment of need.

Standards

Romania does not have standards specific to assessment of need, however they have developed mandatory minimum standards for organisations working in the area of child protection. In 2006, the National Authority for Child Protection and Adoption (ANPDC) published *Mandatory Minimum Standards on Case Management in the Child Welfare Sector*.(263) The standards specify that a case manager will be appointed by the General Directorate for Social Assistance and Child Protection (DGASPC) and outlines the case manager's role in ensuring the coordination of social assistance and carrying out special protection activities in the best interests of the child. There are 12 standards; each standard includes the desired outcome, procedures for implementing the standard and indicators for achieving the standard.(263) The 12 standards are as follows:

1. conditions of use of the method (this covers the techniques, procedures and working tools to ensure a multidisciplinary and integrated approaches).
2. stages in case management
3. identification, initial assessment and case taking
4. detailed/complex assessment
5. multidisciplinary team
6. individual protection plan and service plan
7. monitoring and reassessment
8. post-service monitoring and case closure
9. recruitment and employment
10. main responsibilities and delegating responsibilities
11. initial induction and ongoing training
12. supervision.

The standards set out the role of case managers in monitoring the implementation of the individualised support plan and the delivery of services until supports are no longer required. They highlight the need to maintain open communication with the child and the family while also maintaining relationships with health and social care professionals.

Strategies

The *National Strategy for the Rights of Persons with Disabilities "An equitable Romania", 2022-2027* (2022) is Romania's first strategy on the topic of disability inclusion that reflects the lived experiences of people with disabilities.(253) The strategy was developed to ensure the implementation of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).(2) It outlines priority areas including children's education rights, access to public services and healthcare services for people with disabilities. The general objective of the 2022-2027 Strategy is to ensure the full and effective participation of people with disabilities, with the freedom to make choices, in all aspects of life, in an accessible and resilient environment.(253) The 2022-2027 Strategy promotes a number of principles including:

- non-discrimination and equal treatment
- equal opportunities
- an integrated approach
- respect for the dignity and autonomy of the individual
- full and effective participation and integration in society
- respect for diversity and acceptance of persons with disabilities
- consultation and involvement of persons with disabilities.

The strategy sets out a general objective to ensure an adequate standard of living for people with disabilities and equality. This area includes a specific objective to improve the availability of benefits to cover additional costs related to living with a disability through existing programmes, such as the disability assessment. The strategy also identified a number of challenges including problems encountered with the disability assessment methodology, in which two key issues were identified:

- the initial assessment for disability supports is based on a medical approach to obtaining a disability certificate
- while there are tools for identifying needs, setting goals, planning the provision of services and monitoring their implementation, they are not currently being used appropriately.(253)

Although, in principle, the disability assessment and the classification of a disability is based on a medical-psychosocial model, research to inform the strategy found that in practice a medical model is mainly followed.(253) The 2022-2027 strategy outlines a number of measures, indicators and timelines in order to achieve specific objectives, including a revision of the disability assessment system based on the medical-psychosocial model, specific individual needs determined by the types of disability and a holistic approach.(253)

3.8.5 Regulation, monitoring and inspection of assessment of need

In Romania, the National Agency for Payments and Social Inspection (ANPIS) is a public institution that aims to ensure equal access to social services and benefits to all Romanians in line with legislation, and improve the quality of life for those that are disadvantaged.(264) The ANPIS works on behalf of the Ministry of Labour and Social Justice. At local level, 41 ANPIS agencies coordinate social assistance benefits and state allocated funds for social assistance. The local agencies also organise and conduct thematic and evaluation inspections to monitor the quality of social services to ensure they meet the specific quality requirements according to the service.(264) In monitoring services, the ANPIS apply sanctions as appropriate and provide support to services to meet requirements.

The ANPIS monitor the Complex Evaluation Service within the General Directorate for Social Assistance and Child Protection (DGASPC) against the *Mandatory Minimum Standards on Case Management in the Child Welfare Sector* (see section 3.8.4 for more detail on these standards) and relevant legislation as outlined in section 3.8.3. Where a service is reported to be non-compliant by individuals or legal entities, the ANPIS may organise unannounced inspections.(264) The ANPIS inspect central and local public administration authorities, public and private professionals working in social services and public and private social service providers.

3.8.6 Findings from reviews

This section provides detail on a number of reviews and reports that have been conducted in relation to the disability assessment in order to obtain a disability certificate in Romania. These reports include:

- The Academic Network of European Disability Experts (ANED) Task 2017-18 Disability assessment – country report (2018)
- Designing a Website to Increase the Accessibility of Romanian Disability Certificates (2022)
- Diagnosis of the situation of persons with disabilities in Romania (2021).

The Academic Network of European Disability Experts (ANED) Task 2017-18 Disability assessment – country report (2018)

In 2019, the Academic Network of European Disability Experts (ANED) published a country report on disability assessment in Romania.(258) The report outlines and reviews the forms of disability assessment in use in Romania, including the assessment of type and level of impairment (disability assessment).

The report found that, in 2016, the Romanian Government made amendments to the disability assessment, with the aim of improving the process, for example they increased the time period for re-assessment and they reduced the administrative effort and cost for both beneficiaries and the public administration. Despite these changes, the report found further issues with the assessment processes, with discrepancies and irregularities in files as a result of poor administrative practices. Files that were received and verified by the General Directorate for Social Assistance and Child Protection (DGASPC) were incomplete, missing paperwork or had outdated contact details for the person.(258)

ANED also reported some positive elements to the assessment process.(258) The report highlighted that the person is assessed not only on the level of functionality or impairment, but also on their wider social needs for example, activities, limitations and social integration where possible. Additionally, they noted that the evaluation is not limited to medical aspects, rather it is a complex, multi-disciplinary approach including: social assessment, medical assessment, psychological assessment, vocational assessment, assessment of the level of education, assessment of the skills and level of social integration which the person being assessed is involved in at each stage. They also highlighted that there is a mobile team that travels to the person's home to undertake the assessment when the person cannot come to the institution’s premises.

Designing a Website to Increase the Accessibility of Romanian Disability Certificates (2022)

In 2022, Worcester Polytechnic Institute (WPI), published a report which proposed a digital tool to assist Romanians with disabilities seeking a disability certificate.(257) The report noted that Romania has a low reported percentage of people with disabilities (4%), however this low number may be due to the fact that Romanian disability demographics only include people with a government-issued disability certificate. The report highlighted that there is a significant lack of information available on the current supports in place for people with disabilities in Romania, leaving people unaware of their rights or how to obtain supports and benefits such as a pension, educational and employment accommodations, and transportation benefits.(257) One of the objectives of this report was to identify the challenges people face when seeking a disability certification in Romania. Following engagement with people with disabilities and non-governmental organisations (NGO), the following challenges were identified:

- applicants for the disability certificate are confused about the process; there are insufficient definitions for medical and legal terminology found in online resources regarding the process, resulting in a lack of understanding overall
- there is no system to centralise and synchronise the information on the process; some online resources supply incorrect information due to their own lack of knowledge of the process
- mismanagement of documents can create disruptions and delays to progress through the certification steps; overall the process is complex and can result in missing documents, due to the large amount of paperwork required for an application.(257)

Diagnosis of the situation of persons with disabilities in Romania (2021)

In 2021, the Ministry of Labour and Social Protection commissioned the World Bank to undertake a study to analyse the extent to which the rights of persons with disabilities are respected in Romania.(256,265) The findings of this study were used to inform the National Strategy for the Rights of Persons with Disabilities.(253) The study identified challenges related to social services and independent living in Romania, such as inadequate services and limited access to sheltered housing for some people with disabilities. The report also found that some people with disabilities are living in residential institutions and that this is inappropriate to their needs.

In Romania, people with disabilities are entitled to specialised services, such as the early detection of their disability (pre and post-natal screening), special medical devices, and habilitation or rehabilitation services to enable independent living. This study identified limited access to treatment and public health services to prevent, diagnose, and treat medical conditions and limited access to treatment with dignity and respect.(257)

3.8.7 Key findings

In Romania, legislation sets out the right for people to avail of social benefits and or services designed to support people with disabilities, and the disability assessment required in order to qualify for these services. It also sets out the role and organisation of the General Directorate for Social Assistance and Child Protection (DGASPC), responsible for facilitating assessment of need, and provides the biopsychosocial criteria of the disability assessment.(249,250,251) The DGASPC conduct disability assessments at local level. The disability assessment for children is holistic in nature, combining an assessment of medical evidence with an assessment of the child's abilities and biopsychosocial criteria. The assessment focuses on function, integration, and the participation of the child in the community. Romania has developed *Mandatory Minimum Standards for case management for organisations* *working in child welfare* and the DGASPC is monitored against these standards and relevant legislation. Romania launched the *National Strategy for the Rights of Persons with Disabilities 'An equitable Romania', 2022-2027*.

There are a number of lessons for Ireland that can be drawn from the Romanian system. Legislation supports and promotes the holistic approach to assessment of need for children with disabilities. Legislation sets out the requirement for a biopsychosocial model and the biopsychosocial criteria for classifying children with a disability.(251) As such, the biopsychosocial model is used and implemented nationally. Some issues were identified in relation to adult assessments; assessments for adults with disabilities are mostly based on medical criteria, and rather than looking at the person's functionality, it is a deficit-based approach.

While there are no standards specific to assessment of need, *Mandatory Minimum Standards on case management* set out the stages of case management and the processes and procedures case managers are mandated to follow.(263) Notably for Ireland, the standards aim to ensure that the case manager coordinates support services in the best interests of the child. On receipt of an application for a disability assessment, a case manager in the DGASPC is assigned to the child and remains with the child throughout the process and for the duration of the certificate, where a certificate is granted. The case manager ensures information is shared appropriately and manages the relationship with the child and their family with the professionals providing care and support.

3.9 Hong Kong

This section describes the organisation and delivery of assessment of need services in Hong Kong. This section is set out under the following headings:

- overview of assessment of need
- the model of service
- relevant legislation
- standards, guidance, frameworks, strategies and policies
- regulation, monitoring and inspection of assessment of need
- findings from reviews
- key findings.

3.9.1 Overview of assessment of need

During the course of the review, no legislation relating to assessment of need in Hong Kong was found. In Hong Kong, children under the age of 12 who are believed to have special needs and or disabilities can be referred by a clinician to a Child Assessment Service (CAS), which operates under the remit of the Hong Kong Department of Health. If needs are identified following comprehensive assessment by a multi-disciplinary team, CAS refer children to relevant health services, education and training, and family support services. CAS is monitored by the Health Bureau in Hong Kong. Special educational supports for school-aged children are arranged separately by the Education Bureau. In 2023, the population of Hong Kong was 7.5 million; it was reported in 2020 that 7.1% (534,000) of the population are people with disabilities.(266,267)

3.9.2 The model of service

This section sets out the model of service under the following headings:

- structure and governance of assessment of need
- scope of assessment of need
- assessment of need process
- appeals process.

Structure and governance of assessment of need

There are 31 Maternal and Child Health Centres (MCHCs) throughout Hong Kong which provide ‘developmental surveillance’ for children from birth to five years.(268)

The Department of Health's Child Assessment Service (CAS) identifies those under 12 with special needs and or disabilities.(269) Once needs are identified, there are a number of support services available for children from birth to six years. When children reach school age, the Education Bureau takes over responsibility for arranging special educational need supports in mainstream schools or placement in special schools.

Scope of assessment of need

The services provided by the CAS include:

- assessment for diagnosis and functional evaluation of abilities and disabilities
- therapy and training for selected children
- developmental guidance, counselling and support for parents
- referral of children and parents to appropriate agencies for medical, developmental, educational and social services.(270)

The Social Welfare Department website provides information to families on relevant developmental services.(271)

The Central Referral System for Rehabilitation Services, administered by the Social Welfare Department, manages the central waiting lists of day and residential services for people with disabilities to ensure uniformity in referral procedure and service admission criteria.(272) Referrals can be made by CAS, social workers of medical social services units, integrated family services centres, special schools or rehabilitation service units. The Central Referral System organises entry to the early years services listed below; most are free, with a nominal charge (HK$148 or about €18 per annum) for an Early Education and Training Centre.

Following referral as outlined above, an Early Education and Training Centre serves children with disabilities from birth to the age of two, providing them with early intervention programmes.(273) Children between two and six who have not yet started primary school or preschool can also receive the service. An integrated programme in Kindergarten-cum-Child Care Centre provides training and care to children with mild disabilities with a view to facilitating their future entry into mainstream education.(274) On-site preschool rehabilitation services are provided at participating preschools or kindergartens by interdisciplinary service teams (occupational therapists, physiotherapists, speech therapists, educational psychologists, social workers and special child care workers) for children under six with mild disabilities.(275) A special child care centre provides whole-day training and care for children with moderate to severe disabilities to help prepare them for primary education.(276) These serve children aged two to six with moderate to severe disabilities.

Assessment of need process

The first assessment is by a nurse, and aims to assess the child's developmental status.(277) It collects information about the child, including development, growth, health status, learning, behaviour and family status. This information is then considered at a Team Intake Conference and a comprehensive assessment by appropriate professionals is arranged. There is a fee of HK$135 (€16) for first attendance and HK$80 (€9) for subsequent appointments.

The professional multidisciplinary team conducts appropriate assessment, makes professional diagnoses and formulates follow up-plans and rehabilitation programmes for children according to their developmental issues. Child developmental assessment may include:

- gross motor skills
- fine motor skills
- speech, language and communication
- emotion and behaviour
- social skills
- self-care skills
- attention, cognition and learning
- hearing function
- visual function.

The Child Assessment Service (CAS) has adopted a triage system to ensure that children with urgent and more serious conditions are accorded with higher priority in assessment with a view to enhancing service efficiency. The actual waiting time depends on the complexity and conditions of individual cases.

There are services to support parents to care for their child's developmental needs. Examples include a learning platform with videos on techniques and methods of positive parenting, a series of training programmes designed to increase parents' knowledge of child development, teaching practical skills so as to enhance parents' confidence to manage children's problems and develop their potential, and interim support groups and workshops. A World Health Organisation (WHO) designed training programme running in Hong Kong for parents of children with autism spectrum disorder is currently part of a randomised-controlled trial (RCT) to evaluate its effectiveness.(278) At the time of writing, there are no outcomes available from this trial.

There are three main types of follow up and referral following assessment. These are referral to:

- specialist medical services, for example, ENT services or physiotherapy
- education and training, for example, integrated programme in a Kindergarten, preschool rehabilitation services; or special education under the Education Bureau
- family support services.

Private assessments can be carried out by registered paediatricians, psychiatrists, clinical psychologists or educational psychologists. They can make referrals to the Social Welfare Department or Education Bureau in order to arrange appropriate education or training services to the children.

Appeals process

Parents or patients can send feedback and complaints to the Client Relations Division of the Child Assessment Service, under the Department of Health. This division is dedicated to handling complaints and feedback from the public. If they have any complaint about the training services or school placements, they can also appeal to the Social Welfare Department or the Education Bureau. They can also lodge complaints with the Equal Opportunities Commission, Medical Council or Supplementary Medical Professions Council in Hong Kong if they have complaints involving discrimination or professional misconduct.

3.9.3 Relevant legislation

The Disability Discrimination Ordinance 1995 is the key piece of legislation in relation to disability rights in Hong Kong.(279) The law protects against discrimination on grounds of disability, including in education. There was no legislation found relating to assessment of need.

3.9.4 Standards, guidance, frameworks, strategies and policies

The Child Assessment Service has clinical protocols to guide practice and regularly carries out internal quality assurance exercises. All professionals in the public and private sectors must observe the codes of conduct of their professional bodies as well as all the relevant ordinances and regulations in Hong Kong.

In terms of policies, *The Persons with Disabilities and Rehabilitation Programme Plan* was adopted in 2020 and sets out the strategic direction to address the service needs of people with disabilities.(280) Strategic Direction I is to provide timely and appropriate support to equip people with disabilities with the ability to cope with changes at different stages during their lifespan. This includes preschool rehabilitation services and support for transition from kindergartens to primary school. Recommendations include increased resources with a view to achieving ‘zero waiting time’ for such services. Regarding transition to primary school, the strategy recommends establishing a mechanism for information transfer from preschool rehabilitation services units to primary schools (noting strengthened collaboration between the Education Bureau, Social Welfare Department, Hospital Authority and Child Assessment Services). There are no recommendations specific to assessment of need.

3.9.5 Regulation, monitoring and inspection of assessment of need

The Child Assessment Service under the Department of Health is monitored by the Health Bureau in Hong Kong. In accordance with the Disability Discrimination Ordinance and the Code of Practice on Education, it is unlawful for educational establishments to discriminate against a person with a disability. As such, all educational establishments are obliged to provide equal educational opportunities for eligible students, including those with special educational needs.

3.9.6 Findings from reviews

No recent reviews of child assessment services were identified in the course of this review. A 2015 academic review of the evolution of clinical, training and educational services and research programme for autism spectrum disorders in Hong Kong noted that there was a waiting time of 12-24 months for initial developmental assessments.(281) The *Persons with Disabilities and Rehabilitation Programme Plan (RPP)* sets out strategic directions and measures to address the service needs of persons with disabilities, and it is under regular review by the Labour and Welfare Bureau.(280)

3.9.7 Key findings

In Hong Kong, child developmental screening carried out in Maternal and Child Health Centres – which serve children up to the age of five years - provides a pathway to further assessment. Following referral from MCHCs or other physicians, Child Assessment Services then provide comprehensive assessment for children up to the age of 12, and referral to appropriate medical services, education and training, and family support services. Once children reach school age, their educational supports are arranged separately by the Education Bureau.

It is notable for Ireland that the Central Referral System for Rehabilitation Services manages the central waiting lists of day and residential services for people with disabilities to ensure uniformity in referral procedure and service admission. While there are indications of historic delays in assessment, with waiting times from 12 to 24 months, there are a range of developmental and educational supports available for children from birth to six years (the age of compulsory schooling). As such, the pathway from assessment to service provision is clear, and reviews are undertaken before children transition to school-aged services. Among further lessons for Ireland are the supports provided to parents and caregivers following assessment, alongside the formal developmental and educational supports arranged for children. Providing developmental guidance, training and support for parents and caregivers is one of the four services provided by Child Assessment Services alongside assessment, therapy and training for children, and referral to medical, developmental, education and social services.

3.10 Singapore

This section describes the organisation and delivery of assessment of need services in Singapore. This section is set out under the following headings:

- overview of assessment of need
- the model of service
- relevant legislation
- standards, guidance, frameworks, strategies and policies
- regulation, monitoring and inspection of assessment of need
- findings from reviews
- key findings.

3.10.1 Overview of assessment of need

During the course of the review, no legislation relating to assessment of need in Singapore was found. The Healthcare Services Act 2020 (HCSA) sets out the role and responsibilities of healthcare services. In 2023, the population of Singapore was 5.9 million people; it is estimated that 3% of the population are people with disabilities.(282,283)

Disability services lie within the remit of the Ministry of Social and Family Development and include early intervention services for children, such as support for medical and healthcare services, caregiving services and residential care services.(284) Supports for children include the Early Intervention Programme for Infants and Children (EIPIC), Development Support (DS) and Learning Support (LS).(285) Early intervention services may be provided by Voluntary Welfare Organisations. SG Enable is the first-stop and focal agency for disability in Singapore; it raises awareness on disability issues and facilitates access to disability schemes and services.(286) SG Enable was set up by the Ministry of Social and Family Development in 2013. All children from 0-6 years in Singapore receive developmental screening at seven touchpoints over that period and are referred for further assessment if needed.

While there were no standards for assessment of need found in Singapore, professional practice guidelines have been developed for conducting assessments for preschool-aged children and for educational placement of those over six years with special educational needs. These include *Developmental and Psycho-Educational Assessments and Provisions For Preschool-Aged Children* (2021) and *Psycho-*

Educational Assessment and Placement of Students with Special Educational Needs (6-18 years) (2018).(287,288)

The Early Childhood Development Agency (ECDA) is the regulatory and developmental authority for the early childhood sector in Singapore and oversees key aspects of children's development below the age of seven across both kindergartens and child care centres.(289) It also oversees the provision of government-funded early intervention services for children with developmental needs. The ECDA is jointly overseen by the Ministry for Education and the Ministry of Social and Family Development.

Reviews of assessment of need in Singapore reported delays in accessing early intervention services in Singapore and a general lack of expertise and human resources to keep pace with the demand for early assessment and early intervention services.

3.10.2 The model of service

This section sets out the model of service under the following headings:

- structure and governance of assessment of need
- scope of assessment of need
- assessment of need process
- appeals process.

Structure and governance of assessment of need

Child Developmental Screening (CDS) is conducted as part of preventive care for all children, with the aim of identifying children at risk of developmental delay for early intervention. All eligible Singapore citizens and permanent residents (birth to six years) receive free CDS at government-funded polyclinics and or Community Health Assist Scheme (CHAS) GP clinics.

Scope of assessment of need

Each child developmental screening visit in the first six years (seven visits in all) includes a combination of growth monitoring, physical examination and developmental check on the four domains: personal-social, fine motor, gross motor and language. These screenings are typically conducted together with the recommended childhood vaccinations.

For older children, the Ministry of Education directs parents to private assessments for special educational needs and states that applicants can be eligible for subsidies if they are referred for hospital assessments by (government-funded) polyclinics and Community Health Assist Scheme (CHAS) clinics.(290) Parents and guardians are directed to professional assessments from hospital-based doctors, psychologists and therapists, or by private professionals registered with the Singapore Register of Psychologists. Assessments should be carried out in line with the following professional practice guidelines: *Developmental and Psycho-Educational Assessments and Provisions for Preschool-Aged Children (0-6 years)* and *Psycho-Educational Assessment and Placement of Students with Special Educational Needs (6-18 years)*.(287,288)

Assessment of need process

For children at risk of developing moderate to severe developmental needs, Early Intervention Programme for Infants and Children (EIPIC) provides social, educational and therapy services. The child's progress is monitored through an individual education plan developed jointly with parents. The Development Support (DS) and Learning Support (LS) programmes support children with mild developmental needs, to prepare them for entry into mainstream primary schools.

Early intervention specialists are professionals trained at postgraduate level who work in integrated early childhood intervention services at the intersection of the health, education and protection sectors, to provide individualised services to parents and infants or toddlers with developmental delays or disabilities, often through home visits. Among others, they conduct developmental screenings and refer children to early intervention services. They also conduct comprehensive assessments, prepare individualised family service plans and prepare transition plans to inclusive preschool and primary education.(291) Doctors, both generalists and paediatricians, also carry out developmental screening and refer children to specialised early intervention services.

Developmental screening is carried out by healthcare professionals in polyclinics. General practitioners and paediatricians who assess a child's developmental progress use the developmental checklists in the Child Health Booklet – a personalised databank of health records provided for every baby at birth - which is based on the Denver Developmental Screening Test, the only tool standardised for the local Singapore population.(292)

Children with observed developmental delays are referred to specialists for detailed assessment and further management. A comprehensive developmental assessment is typically conducted at hospitals and includes medical diagnosis as well as assessments for early childhood screening and outcome monitoring. The number and type of assessments to be conducted depend on a number of factors, such as:

- the child's presenting issues

- the child's age and developmental, behavioural or learning needs
- the relevant specialty of the professional seeing the child.

As of 2021, there were five community-based intervention centres attached to the Child Development Unit of the National University Hospital (NUH) and the Department of Child Development, KK Women's and Children's Hospital (KKH).(293) These centres provide Early Intervention (EI) at the tertiary level following comprehensive assessment. Children with mild developmental problems may be discharged after a short period of intervention. Children with more complex issues who are likely to require a longer period of support will continue appropriate intervention in partnership with parents until they are enrolled in EIPIC centres. SG Enable arranges placement in an EIPIC centre nearest to the child's home.

Practitioner guidelines state that to obtain a holistic understanding of a child, assessment approaches should make use of diverse assessment methods and gather information from multiple sources. Professionals should obtain information about the child's functioning and skills in daily activities and routines, across different environments such as the child's home, childcare, preschool, EI centre, and or in community settings.(288) Information may be gathered in the following skills and areas of functioning considered necessary or important for the child's development:

- cognitive skills (for example, intellectual capacity, memory, attention, concentration skills)
- language and communication skills (for example, receptive and expressive skills)
- academic skills (for example, literacy, numeracy)
- social, emotional, behavioural and interpersonal functioning
- adaptive behaviour
- health and body state factors, including motor and sensory difficulties, energy level
- strengths, motivation and interests.

The guidance states that, where appropriate, children's views on their own interests, strengths, and difficulties, should be sought. In addition to child-specific factors, assessments should also look into the environment of the child and its impact on the child's learning and development.

Development Support - Learning Support (DS-LS)

A preschool child with mild developmental needs may be identified for a Development Support - Learning Support programme by a teacher or paediatrician, and with parental consent. Children are screened by early intervention professionals using screening tools, interviews with the early setting educator and observation of the child in school. All cases screened are presented to a multi-disciplinary team at the case filter meeting. The team collectively makes decisions on the type of support the child will need:

- For a child requiring learning support, a statement of needs that denotes the needs of the child is issued by an educational psychologist during the case filter meeting.
- For a child requiring development support, a referral to the relevant hospitals is made for the child to receive further consultation from a paediatrician. The statement of needs is issued by the paediatrician during a clinic visit.
- For a child who requires higher level or other services (such as psychological issues like anxiety, depression or trauma), the paediatrician makes referrals to the necessary departments within the hospital for relevant support including trauma or psychiatric evaluation, under the paediatrician's care management, when needed.

Based on the decisions made at the case filter meeting, the social worker or case manager arranges to meet the parent or caregiver of the child to share details of the programme and finalise the enrolment decision. The social worker or case manager will also gather more information about the child (for example, family background or socio-economic status) from the preschool and or parent or caregiver. The discussion may involve the educator, early intervention professional and or health and social care professional as necessary.

A key part of the programme is reviewing the intervention goals set in a child's individualised education plan and documenting the progress made, as a team. This includes an evaluation of where the child is at upon completion of the intervention. An end of intervention report is provided to the parent or caregiver and educator.

EIPIC Programmes

The EIPIC programmes target children who require medium to high levels of early intervention support, where the programmes aim to increase the developmental growth potential of the child, minimise the development of secondary disabilities, and maximise integration in mainstream settings. They are for children from birth to six years who are assessed by a paediatrician to be at risk of a developmental, intellectual, sensory or physical disability, or a combination of disabilities.

Paediatricians who have assessed a child to have developmental needs or disabilities can, with parent or caregiver's consent, refer the child to SG Enable for a suitable EIPIC service. Depending on his or her age and needs, the child can be supported under the EIPIC@Centre, EIPIC Under-2s, or home-based early intervention. The EIPIC@Centre programme is for children aged 24 months to six years, and a trans-disciplinary team of early intervention professionals and health and social care professionals provide support. Caregiver support and training is also provided. The under-twos programme also includes home visits. For those not suited to centre-based intervention, early intervention professionals and health and social care professionals may deliver two to four hours of early intervention a week and caregiver coaching, in the home setting.

Progress of the child is monitored periodically, typically through the Early Childhood Holistic Outcomes (ECHO) Framework, sometimes alongside the Assessment, Evaluation, and Programming System for Infants and Children and or other complementary tools and checklists.(294,295) The ECHO Framework is an early childhood intervention service framework based on the Early Childhood Outcomes (ECO) framework used by the US Office of Special Education Programme and adapted to the Singapore context. It involves observations of routines in the early intervention centre and or home; parent or caregiver interviews; and information from any other assessment measures and reports. The data is collated and summarised, and the child's development is evaluated and compared to age expectations.

This data is then translated into a global child outcomes rating for each of the three global child outcomes, namely:

- having positive social-emotional relationships
- acquiring and using knowledge; and
- having appropriate behaviour to meet needs.(296)

Given the importance of parent or caregiver involvement, family outcomes are also monitored, namely:

- understanding their child's strengths, abilities and special needs
- helping their child develop and learn
- knowing how to communicate their child's needs to others, and accessing relevant services and support.

The EIPIC programme offers two main types of intervention support: learning support services delivered by the early intervention professionals, and the developmental support services delivered by health and social care professionals such as speech and language therapists, occupational therapists, educational therapy professionals, educational psychologists, with in-class support conducted by the early intervention professionals. There are early intervention professionals who may also be trained educational psychologists.

Transition from early intervention services to school-aged provisions

Discussion around school-aged provisions typically begin around the age of five (the age of compulsory schooling is six years of age). The transition process from early intervention to school-aged provision includes assessments conducted at various stages to systematically gather relevant and valid information about a child's strengths and needs. The purpose of these assessments is to assist with appropriate educational planning for the child and to inform decisions regarding transition, education placement and recommendations for support at the school-going ages. These assessments are typically conducted by professionals in hospitals and or early intervention centres for children approaching the school-going age.

Appeals process

No information was found on an appeals or a complaints process in this review.

3.10.3 Relevant legislation

The Healthcare Services Act 2020 regulates the provision of health services, as set out in Section 3.10.5.(297) Singaporean legislation does not have an official definition of disability.

3.10.4 Standards, guidance, frameworks, strategies and policies

There were no specific standards for assessment of need, and the guidance found relates to conducting assessments for specific groups of children, such as the *Developmental and Psycho-Educational Assessments and Provisions for Preschool-Aged Children (0-6 years)* and the *Psycho-Educational Assessment and Placement of Students with Special Educational Needs (6-18 years)*. In relation to strategies, the Enabling Masterplan 2030 is the current national roadmap to creating a more inclusive Singapore, and is the fourth such plan.

Guidance

As noted, there are professional practice guidelines for conducting assessments for preschool-age children, these are the *Developmental and Psycho-Educational Assessments and Provisions For Preschool-Aged Children* (2021).(288) The guidelines were produced by a workgroup including the Ministry of Social and Family Development, the Early Childhood Development Agency, the Minister of Education and professionals from the health, education and social services sectors. The guidelines are intended for use by professionals in the Early Intervention (EI) sector. This includes medical and health and social care professionals, for example, occupational therapists, speech and language therapists, and psychologists, and other professionals who are involved in advising parents about interventions and provisions for children with developmental needs. The detail of the guidelines is set out in Section 3.10.2.

There are also professional practice guidelines for educational assessment and placement of students with special educational needs, these are the *Psycho-Educational Assessment and Placement of Students with Special Educational Needs (6-18 years)* (2018).(287) The document does not include standards for assessment for therapy and social care.

Strategies and policies

The *Enabling Masterplan 2030* is a disability strategy developed by the Ministry of Social and Family Development.(298) It sets out the vision for Singapore as an inclusive society in 2030. The strategy has 29 recommendations and has specific targets and indicators for tracking progress across 14 areas. There is no specific reference to assessment of need.

3.10.5 Regulation, monitoring and inspection of assessment of need

The early childhood sector is regulated by the Early Childhood Development Agency (ECDA) which oversees key aspects of children's development below the age of seven across kindergartens and child care centres. The ECDA can conduct investigations of incidents involving child mismanagement, with powers to issue warnings, financial penalties, shorten licence tenure or revoke licences.

The provision of healthcare services is regulated by the Ministry of Health, under the Healthcare Services Act 2020 (HCSA). There are four modes of service delivery under the Act: permanent premises; conveyances (for example, ambulances); temporary premises (for example, treating patients at home); and remote (for example, virtual GP consultation). Under the Act, healthcare providers need to apply for approval to hold licences for the licensable healthcare services they provide, as well as the appropriate modes of service delivery. Full implementation of the Act is being rolled out into 2024. Under the Act, inspections are risk-based and are not linked to license renewal.

No information was found on monitoring or inspection of assessment of need specifically.

3.10.6 Findings from reviews

There is evidence of delays in accessing early intervention services in Singapore. The Early Childhood Development Agency (ECDA) guide for parents notes that there can be a wait of at least six months after referral for a government-funded Early Intervention Programme for Infants and Children (EIPIC) Programme.(299) *Vital Voices for Vital Years 2* (2019) is a study conducted by the Lien Foundation on improving the early years sector.(300) This qualitative study used interviews with 35 leaders across health, social services and education to examine developments and challenges in the sector. It identified a general lack of expertise and human resources to keep pace with the demand for early assessment and early intervention services. It also identified much variability in the quality of early intervention services provided by different Voluntary Welfare Organisations. It noted that child health and early intervention service delivery was predominantly hospital or centre based, which can interrupt the child's day in preschool and can be inconvenient for families. The report also noted that EIPIC centres were separate from preschools, though many children were enrolled in both, and so a more integrated system of care and support was needed.

A 2021 academic paper on the early childhood developmental intervention system in Singapore identified five key principles to its approach:

- shifting the decision-making power on caring for the child from the professional to the family (family-centred)
- shifting diagnosis-based intervention to one that is based on the developmental needs of the individual child
- shifting emphasis of intervention from disability to functional and developmental performance, participation and quality of life
- shifting the settings of service and care delivery to a less restrictive, more natural and inclusive environment (for example, childcare centres, pre-schools and schools, homes and the community)
- shifting from a multidisciplinary to a transdisciplinary team practice.(293)

The paper describes the child development programme as responding to health challenges by going beyond hospital-based care into the community, with a focus on structured integration of medical services with education, and social and community support. The paper highlights that the child development programme also includes a focus on the need for a strong collaborative partnership with parents and caregivers.

3.10.7 Key findings

Universal child developmental screening provides seven touchstones for screening of children from birth to six years. The Child Health Booklet, issued at birth, also provides parents with a means of observing how children are meeting developmental milestones. Children with developmental delays are referred for further assessment and screening as appropriate. The Development Support - Learning Support (DS-LS) and EIPIC programmes provide a continuum of support for mild to moderate to severe needs, and a roadmap for transition between levels of service and stages of education, for example, from preschool to primary education. However, there are out-of-pocket expenses incurred in accessing these programmes, albeit with subsidies available to those on lower incomes, and some indications of waiting times to access services.

The practice guidelines for practitioners indicate the standard expected, but their recommendations are subject to professional judgement and codes of practice. The Early Childhood Development Agency regulates the early childhood sector but there was no information found on monitoring or inspection of assessment of need.

A 2021 paper on the early childhood developmental intervention programme highlights some strengths of its holistic approach. Some medical services are integrated with education and community support, with an emphasis on supporting and involving parents and caregivers. Intervention is based on needs rather than diagnosis, with families are central to decision making. Additionally, there is a focus on strengths and participation rather than disability. Of relevance, service delivery is now moving to preschool and home settings with transdisciplinary teams in place to support this.

3.11 Summary of findings from the approaches to assessment of need internationally

The approaches to assessment of need internationally set out in this document provide an overview of how England, Scotland, Wales, Northern Ireland, Australia, New Zealand, Iceland, Romania, Hong Kong and Singapore deliver assessment of need in their jurisdictions. The review shows that these jurisdictions have legislation, guidance and processes in place to facilitate assessment of need. The main findings from the international jurisdictions are:

Legislation

In most jurisdictions reviewed, assessment of need is legislated for in some format, either directly or through the process of accessing state-funded services. Legislation in England, Scotland and Northern Ireland, for example, is centred on the needs of children and their families; it defines the responsibility of the local authorities and other agencies to safeguard and support children, to carry out an assessment of need where requested and to undertake multi-agency working to assess and meet needs. In Australia, New Zealand and Romania, legislation sets out the right for people to access state funded services and or direct funding; legislation also sets out the process to access services, which includes the assessment of need process. In Iceland, legislation specifies the right for people with disabilities to receive early support, intervention and diagnosis.

Jurisdictions are demonstrating a move away from a diagnostic approach to assessment of need, to one based on the person’s needs. Legislation in Iceland is found to support this, stating that the child's support needs must be met, even if there is no diagnosis or assessment. Similarly, in England, it is not necessary for an assessment to be fully completed before beginning to deliver services, where needed. Jurisdictions are also focusing on a system-wide approach to assessment of need, with legislation introduced to support integrated assessments and service delivery, and multiagency working to deliver assessment of need and services; examples are found in the UK and in Iceland. In Romania, legislation promoting a holistic approach to assessment of need for children with disabilities sets out the biopsychosocial criteria for classifying children with disabilities and the methods used to calculate the level of disability.

The evidence also shows a heightened focus on improving the assessment of need process, with the introduction of new legislation in some jurisdictions. In Iceland, amendments to the Act on Counselling and Diagnostic Centre enacted in 2022, place a greater focus on early intervention and integration for all children in need of additional support; while the Act on the Integration of Services in the Interest of Children’s Prosperity, also enacted in 2022, sets out the requirement for integrated services.(231,233) In New Zealand, newly enacted legislation, the Pae Ora (Healthy Futures) Act 2022, sets out the new structure and organisation of the publicly-funded health system and the provision of services for all New Zealanders, including those with disabilities and the assessment of need required to access those services.(214)

Holistic approach to assessment of need

In the majority of jurisdictions reviewed, assessment of need is holistic in nature, combining an assessment of medical evidence, social development and family and environmental factors which impact upon the child or young person. Jurisdictions have moved towards a strengths-based approach, focused on the person's abilities, resources, goals and needs. This holistic approach is supported by legislation, frameworks and or guidance, aimed at providing more choice and control to those in need of support. Legislation in Australia, for example, aims to support independence, and social and economic participation, while in Romania, it sets out the biopsychosocial criteria of assessments for children with disabilities. In all UK jurisdictions, three main domains provide a holistic view of a child's situation, they are:

- the child's developmental needs
- parents' or caregivers' capacity to respond to those needs
- wider family and environmental factors.

In New Zealand, assessment of need is underpinned by the Enabling Good Lives (EGL) principles, a person-centred approach that asks what a good life looks like for the person and what their hopes and aspirations are.

In most jurisdictions, holistic assessments are conducted or supported by multi-disciplinary teams, which are selected based on the child's needs. In Romania, for example, teams may include a doctor or paediatrician, a psychologist, an education specialist and a social worker. In England, assessments are carried out by social workers working with other professionals as required, based on the child's needs. In Hong Kong, a professional multidisciplinary team conducts an assessment, makes a diagnosis and formulates follow up plans and rehabilitation programmes for children according to their needs.

Whole-system approach that includes assessment of need

The review found that in all jurisdictions, assessment of need is one part of a process that includes service planning, service coordination and service provision. In the majority of countries reviewed, care and support plans are provided following an assessment; these may include identified needs, outcomes, actions, responsibilities and timelines for agreed services. For example, in England, an education, health and care (EHC) plan is developed following an assessment. In Romania, a complex evaluation report and the proposed Individual Program for Rehabilitation and Social Integration (PIRIS) is drafted. The majority of the jurisdictions also provide for service planning and coordination. In New Zealand, for example, service planning and service coordination are undertaken after the assessment of need has been completed. While part of the process, there is a clear separation between the assessment and service planning and service coordination, to ensure services are planned on the individual's needs and not based on the availability of resources. Other examples can be found in Australia, where, following an assessment of need, a person is assigned a planner who uses the findings from the assessment to generate a budget for the person to spend on supports; if required the person can request support to coordinate these services.

Special education needs

The evidence found that the assessment of special education needs (SEN) is a separate process in the majority of countries reviewed. However, countries such as England, Iceland and Romania have a more holistic approach, where assessment of SEN is combined with the wider assessment of needs. In England, education, health and care (EHC) needs assessment are conducted, which may result in the creation of an EHC plan. These assessments are holistic, multi-agency and child centred, and where an education, health and care plan is required, the local authority has a duty to provide services. In Iceland, assessments are carried out in the child environment by specialists within the preschools or school services, or by health care professionals, and supports are provided based on the child's needs. If more complex needs are identified, a referral is often made by the preschool or school services to the Counselling and Diagnostic Centre (RGR) for a further assessment. In Romania, education forms part of the assessment criteria of the disability assessment. Following an assessment, the General Directorate for Social Assistance and Child Protection (DGASPC) identifies the child's special educational needs which are then organised by the Ministry of National Education and Scientific Research.

In Scotland, Wales, Northern Ireland, Australia and New Zealand, the review found that the assessment of special education needs is separate to the assessment of need process and that challenges exist in some jurisdictions as a result of this. In New Zealand for example, children with special education needs and children with low to moderate needs do not fall under the scope of assessment of need. The Ministry of Education is responsible for providing support and access to education, however the review found that the service provided is inadequate and cannot meet demand.

Standards and guidance

While there are no standards specific to assessment of need in any of the jurisdictions reviewed, many of the jurisdictions have high level health and social care standards and or disability standards. In the UK, there are high level health and social care standards in Scotland, Wales and Northern Ireland; England is in the process of developing national standards on special educational needs and disabilities. Romania has developed *Mandatory Minimum Standards on case management* to set out the stages of case management and the processes and procedures case managers are mandated to follow when facilitating case management processes, including assessments of need. These standards aim to ensure that the case manager coordinates support services in the best interests of the child.(263) In New Zealand, *the Ngā Paerewa Health and Disability Services Standard* provide the foundation for describing best practice and fostering continuous improvement in the quality of health and disability services.(218)

Guidance and codes of practice have been developed across some jurisdictions on the assessment of need process and the preparation of care and support plans, see table 3 below for examples. In England, Scotland and Wales in particular, much of the statutory guidance developed is based on legislation related to assessment of need and sets out the principles of a holistic, strengths-based and integrated approach to assessment of need. Statutory guidance related to the Children and Families Act 2014 and associated regulations in England outlines all the key stages in statutory assessment and planning, and preparing the care plan. In Scotland, statutory guidance sets out the holistic strengths-based approach to the assessment, and explains what wellbeing is in the context of the Children and Young People (Scotland) Act 2014. In Wales, a code of practice related to legislation outlines a model of assessment and care planning based on the person’s strengths and capabilities and what matters to them.

Table 3: Statutory guidance or codes of practice in three UK jurisdictions

Country	**Statutory Guidance / Codes of Practice**	**Features**
Scotland	▪ The Children (Scotland) Act 1995 Regulations and Guidance ▪ Getting It Right For Every Child (GIRFEC) - Statutory Guidance - Assessment of Wellbeing 2022 – Part 18 (Section 96) of the Children and Young People (Scotland) Act 2014	▪ Holistic assessment ▪ Wellbeing indicators set out in legislation (SHANARRI)

	▪ Statutory Guidance to Accompany the Social Care (Self-directed Support) (Scotland) Act 2013	
England	▪ SEND Code of Practice	▪ Holistic assessment ▪ Integrated approach to Education, Health and Care Plan
Wales	▪ Social Services and Well-being (Wales) Act 2014, Part 3 Code of Practice (assessing the needs of individuals) ▪ Social Services and Well-being (Wales) Act 2014, Part 4: Code of Practice (Meeting Needs)	▪ Holistic assessment ▪ Five elements of assessment

Regulation and monitoring of assessment of need

In the jurisdictions where monitoring is in place, assessment of need is included as part of wider monitoring programmes. In England for example, the Care Quality Commission (CQC) and the Office for Standards in Education, Children's Services and Skills (Ofsted) inspect and monitor the local authorities, carrying out joint targeted inspections. Monitoring and inspections review the systems that are in place, rather than individual practitioners or providers, or specific procedures. In Wales, the Care Inspectorate Wales is the regulator of social care and childcare and reviews the performance of local authorities in the delivery of social services functions. Evaluations of the local authorities include reviews of how assessments of need are undertaken, how they inform care and support planning, and the services that children and young people are receiving as a result. During inspections, they review the child's entire journey from assessment to the service provided. In New Zealand, monitoring and auditing of assessment of need and services coordination is carried out by Standards and Monitoring Services (SAMS) against the *Social Sector Accreditation Standards* (SSAS), and the EGL principles. Rather than an auditing agency, SAMS is a national evaluation, education and leadership development organisation governed by people and families with disabilities, whose approach is grounded in the EGL approach.(217) In a number of countries there is no specific monitoring of the assessment of need process, for example Australia and Iceland.

Challenges related to assessment of need

Each jurisdiction reported challenges in relation to assessment of need. While some jurisdictions have introduced legislation, guidance and standards to improve the experience for people with disabilities and enhance services, challenges still remain. In Scotland, Wales and Northern Ireland, recent reviews reported inconsistencies in the assessment of need process across the jurisdictions. For example in Wales, a review of how well local authorities provided early help, care and support for children with disabilities identified variances in the quality of assessment, the quality assurance processes and care and support planning across the country. In Scotland a review of social work services for children and young people with disabilities indicated some variability across the country, and in Northern Ireland, a review of community services for children with a disability reported variation in the assessment process between the Trusts, and the level of service provision following assessment.

Another key challenge faced is long waiting lists for assessments and or access to services. A recent review in England found that many children and families experience long waiting times for some assessments and supports, such as speech and language therapy; local authorities are struggling to meet the demand for assessments and follow-on services. In New Zealand, services reported that insufficient funding, a lack of available services and workforce related challenges have resulted in delays to service coordination and provision, and as such, services cannot meet the demand. A review of the disability support workforce in New Zealand found a workforce that is heavily impacted by staff shortages affecting the entire health workforce, that the sector is experiencing significant transformation with the implementation of EGL initiative and requires additional support to enable a successful system change. Resources are also a challenge in Iceland, where it was reported that there is often a lack of staff to provide services for children with complex needs in remote areas[†††††].

In Australia and Romania, the assessment of need systems were found to be complex and confusing for families trying to access supports. In Australia, a 2023 review reported that the assessment of need and service planning process was described as confusing and frustrating, and that attempts to reform the system were meet with anger and anxiety. In Romania, recent reviews of the disability assessment process highlighted a complex application process and a lack of information available to people with disabilities.

[†††††] This information was provided by subject matter experts from Ráðgjafar-og greiningarstöð Iceland, interviewed on 06 March 2024 to inform this research report.

4. Summary, conclusion and next steps

There are important lessons to be learned and areas for consideration for Ireland from the approaches taken in other countries to assessment of need.

A holistic approach to assessment of need includes consideration of the medical, social, family and environmental factors that impact the person. Many jurisdictions have moved towards a strengths-based approach, focused on the person's abilities, resources, goals and needs. This approach supports the person to access the supports that work best for them and their family.

Robust legislation and policy is required to ensure a best interest, holistic, multidisciplinary and needs-based approach to assessment of need. It is important that people with disabilities have access to a standardised assessment of need and also the services they need to support them. Rather than a standalone process, assessment of need is preferably part of a system that includes service planning, service coordination and service provision. Internationally, there is a move towards a person-centred approach to assessment of need that focuses on support needs rather than diagnosis; this enables early support and intervention. Statutory guidance and codes of practice are used internationally, based on legislation, to set out the principles of a holistic, strengths based and integrated approach to assessment of need.

Internationally, jurisdictions have high-level health and social care standards and or disability standards in place to outline what best practice looks like and to identify areas for quality improvement in disability services. Specific standards for assessment of need were not identified internationally; often statutory guidance, frameworks or codes of practice are in place for assessment of need. Assessment of need is monitored in some jurisdictions, as part of wider, whole system monitoring programmes. These monitoring programmes look at assessment of need, care and support planning and the services that are provided.

Each jurisdiction included in this review faced challenges related to assessment of need. A key challenge found was inconsistent delivery of assessment of need across regions, leading to inequity in care. Long waiting lists and difficulties in accessing services is also seen in many jurisdictions, often due to lack of resources and staffing issues. The assessment of need process is seen as complex and confusing in some jurisdictions and it has been highlighted that the system needs to be person centred and easy to navigate.

This paper describes both the national and international systems for assessment of need, and sets out lessons to be learned and areas for consideration for Ireland from the approaches taken in other countries. The aim of this research is to inform next steps in relation to policy direction for assessment of need. This, in turn, will inform the need for national standards in this area, so that any standards developed have the maximum benefit for people with disabilities and their families.

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Appendices

Appendix 1 – List of the 34 jurisdictions reviewed during the initial scoping review of assessment of need

Jurisdictions				
Australia	England	Hungary	N Ireland	South Korea
Canada	Estonia	Iceland	Poland	Spain
Chile	Finland	Israel	Portugal	Sweden
Costa Rica	France	Italy	Romania	Turkey
Cyprus	Germany	Lithuania	Scotland	United States
Czech Republic	Greece	Netherlands	Singapore	Wales
Denmark	Hong Kong	New Zealand	Slovenia	

Appendix 2 – International organisation contacted to inform the approaches to assessment of need internationally

Organisation	**Jurisdiction**
Needs Assessment Service Coordination Association (NASCA)	New Zealand
NDIS Commission	Australia
National Disability Insurance Agency (NDIA)	Australia
Care Quality Commission (CQC)	England
Department of Health	Northern Ireland
Care Inspectorate Wales	Wales
Care Inspectorate Scotland	Scotland
Ráðgjafar-og greiningarstöð (RGR)	Iceland
Pro ACT Suport	Romania
National Authority for the Protection of Child Rights and Adoption (ANPDCA)	Romania
Department of Health	Hong Kong

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Health Information and Quality Authority
George’s Court
George’s Lane
Smithfield
Dublin 7
D07 E98Y

+353 (0)1 814 7400
info@hiqa.ie
www.hiqa.ie