

Understanding the data: A review of Scotland's statistics

Are disabled children visible in Scotland's children's statistics?



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1. Introduction

Background

The collection of good quality statistics is critical to increasing the awareness and visibility of disabled children and to better understanding their needs. The Scottish Government's [Data collection and publication guidance: Disability](#) paper published in 2022 highlights the importance of good quality statistics by stating:

"Disability statistics are important for monitoring discrimination and inequality. Good quality disability data will help with understanding the issues faced by disabled people...(and)... may also be used to inform policy formulation and service delivery" (Scottish Government, 2022 pp2-3).

As well as informing and influencing national and local policy makers, funders, and leaders and managers of services, having good quality disabled children's statistics can lead to better support for individual children. Identifying and recording a child's disability enables services to better understand the child, make reasonable adjustments, provide supports that meet the child's individual needs, and consequently deliver on their [Equality Act 2010](#) and [Children \(Scotland\) Act 1995](#) statutory duties. Furthermore, if needs are understood and recorded at an early stage in a child's life and/or disability, there are greater opportunities to put in place preventative, early intervention and/or anticipatory support before their support needs increase and longer-term or specialist care is required.

Aims

This paper details a review which assesses the quality of the disabled children's statistical data that is reported across Scotland's children's services. With reference also to comparative UK and international data, the paper:

- Reviews how disability is defined and recorded across Scotland, UK and international statistical collections
- Considers the extent to which disabled children are visible across these statistical collections and, in particular, how visible they are in Scotland's children's care and protection data given that disabled children have been found to have experienced harm and abuse three to four times more than non-disabled children have experienced this (Jones et al., 2012; Sullivan and Knutson, 2000)
- Reports on discussions and workshops held as part of this research with key data providers and stakeholders in Scotland (including the Scottish Government, the Child Protection Disability Network, the Scottish Children's Reporter Administration, and local authorities) to understand the data environment in which disabled children's statistics are captured; and
- Offers next steps for how the collection of disabled children's statistics could be enhanced in Scotland.

How to read this review

Following this introduction, there are seven sections:

- **Section 2** sets the international policy context and in particular how disabled children's statistics feature in the *UN Convention on the Rights of the Child and the UN Convention on the Rights of Persons with Disabilities*. The section concludes with a discussion of how disability is defined in the international literature.
- **Section 3** introduces the *Washington Group / UNICEF Module for Child Functioning* as a means of measuring disabled children and presents the available international statistics provided through the use of the Module.
- **Section 4** presents the disabled children's data contained in Scotland's census and health, early years and education statistics to help understand the size and needs of the population.
- **Section 5** focuses on Scotland's children in need of care and protection and, drawing on comparator data from England, Wales and Northern Ireland, assesses the visibility of Scotland's disabled children in need of care and protection.
- **Section 6** looks within Scotland to explore whether the recording of disabled children varies across local authorities and, if so, consider why there might be variance.
- **Section 7** summarises the different definitions used across Scotland's children's statistical collections to show how these map against each other.
- **Section 8** sets out the conclusions from the paper and offers next steps on how to enhance the collection of disabled children's statistics in Scotland.

The language and terminology used

Throughout this paper, the term 'disabled children' is used because, consistent with the social model of disability (see [Section 2](#)), children are disabled by society or the environment. 'Children with a disability' is an alternative term but, while person- and child-centred, it implies that the disability is something intrinsic to the child (Colver, 2005).

'Looked after' children is the legal definition used to refer to children who are currently in the care of a local authority in Scotland.

Consistent with the UNCRC definition of a child, statistical data has been presented for children aged 0-17 years olds wherever available. Where data for 0-17 year olds is not available, the closest equivalent has been presented.

2. International policy and legislative context

There are two international human rights treaties that have a particular importance for disabled children living in Scotland, their rights and how these are required to be upheld.

United Nations Convention on the Rights of the Child

The [United Nations Convention on the Rights of the Child](#) (UNCRC), adopted by the UN in 1989, and ratified by the UK in 1991, was the first legally binding international instrument affirming, promoting, and protecting children's human rights. It provides a comprehensive body of law, outlining children's civil, cultural, political, social, and economic rights, all of which are interlinked, interdependent, and indivisible. All the rights outlined in the UNCRC apply to all children but, with regards to disabled children, the UNCRC was the first international human rights treaty that specifically referenced disability.

Box 1: Articles of particular relevance to disabled children contained in United Nations Convention on the Rights of the Child (UNCRC)

Article 2, on non-discrimination, is in recognition of the particular vulnerability of disabled children to discrimination.

Article 23 is dedicated wholly to the rights and specific circumstances of disabled children. It states that the realisation of their rights should ultimately lead to enjoyment of full and decent lives, with maximum inclusion in society. It also recognises the rights of disabled children and their parents or carers to special care and/or assistance that is appropriate to their condition and circumstances. This assistance needs to be provided without charge wherever possible and aim at ensuring effective access to education, health, care, training, rehabilitation, recreation and preparation for employment.

Both Article 2 and 23 require States to take appropriate measures to ensure the equal treatment and non-discrimination of disabled children, and to make certain that they live in conditions *"that ensure dignity, promote self-reliance, and facilitate active participation in the community"* (UNCRC General Comment No.5 para 11).

United Nations Convention on the Rights of Persons with Disabilities

Building on decades of work to change attitudes and approaches to disabled people, the [United Nations Convention on the Rights of Persons with Disabilities](#) (UNCRPD) was adopted in 2006, ratified by the UK in 2009, and has played a key role in shifting perceptions of disabled people from objects of charity, medical treatment and social protection, to subjects with rights, capable of claiming those rights and making decisions about their lives. The UNCRPD applies to all age groups and Box 2 outlines the Articles that are most relevant to children.

Box 2: Articles of particular relevance to children contained in United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

The preamble to the UNCRPD recognises, in paragraph 18, that children with disabilities should have full enjoyment of all human rights and fundamental freedoms on an equal basis with other children, and recalls the obligations to that end undertaken by States Parties to the UNCRPD.

Article 3 underlines the general principles of the UNCRPD, including non-discrimination, full and effective participation and inclusion in society, and respect for the evolving capacities of children with disabilities and respect for their right to preserve their identities.

Article 7 recalls the obligation to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with others; that the best interests of the child should be a primary consideration; and that children with disabilities have the right to express their views freely, on all matters affecting them.

Article 19 outlines the equal right of all persons with disabilities to live in the community with choices equal to others, and their right to independent living, underlining States' responsibility to ensure that persons with disabilities have access to a range of in-home, residential, and other community support services necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community.

Article 23 states that children with disabilities have equal rights with respect to family life, that they should not be separated from their parents against their best interests, and never on grounds of disability; and, if alternative care is necessary, every effort should be made to provide it within the wider family, or within the community in a family setting.

Article 24 expresses a recognition of the right of persons with disabilities to education and calls on States to ensure an inclusive education system and lifelong learning.

Article 25 recognises the right to the highest attainable standard of health and calls for undertaking all appropriate measures to ensure access to healthcare services.

Article 28 acknowledges the right to an adequate standard of living and to social protection and requires States to take all appropriate steps to safeguard and promote this right without discrimination.

Article 31 calls on States to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention.

The importance of collecting statistics

Article 31 of the UNCRPD calls on States to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies.

The importance of collecting accurate, standardised data and statistics is also contained in [UNCRC General Comment No. 5](#). General Comments are guidance provided by the UN Committee on the Rights of the Child to help people understand the rights set out in the UNCRC. UNCRC General Comment No. 5 focuses on the implementation of the Convention and states that comprehensive data collection plays a key role in promoting *"the full enjoyment of all rights in the Convention by all children"* (UNCRC General Comment No. 5 para 9) and requires States to *"identify individual children and groups of children (for whom) the recognition and realization of whose rights may demand special measures"*. This can only be achieved if *"data collection is disaggregated to enable discrimination or potential discrimination to be identified."*

The importance of robust and accurate data is also highlighted in the [UNCRC General Comment No. 9](#), which focuses on disabled children. Paragraph 19 reads as follows:

"In order to fulfil their obligations, it is necessary for States parties to set up and develop mechanisms for collecting data which are accurate, standardized and allow disaggregation, and which reflect the actual situation of children with disabilities. The importance of this issue is often overlooked and not viewed as a priority despite the fact that it has an impact not only on the measures that need to be taken in terms of prevention but also on the distribution of very valuable resources needed to fund programmes. One of the main challenges in obtaining accurate statistics is the lack of a widely accepted clear definition for disabilities. States parties are encouraged to establish an appropriate definition that guarantees the inclusion of all children with disabilities so that children with disabilities may benefit from the special protection and programmes developed for them. Extra efforts are often needed to collect data on children with disabilities because they are often hidden by their parents or others caring for the child." (UNCRC General Comment No. 9, para 19).

Defining disabled children

Paragraph 19 of the UNCRC General Comment No. 9 makes clear that there needs to be a widely accepted definition of disability to enable robust data collection. There are, however, competing perspectives within the academic literature on how disability ought to be defined, with three main definitional approaches evident in the international literature: the medical, social, and human rights models.

The medical model of disability views disability as a health or medical condition or body impairment, and statistical measures developed from this perspective record only the presence of specific and diagnosed conditions or impairments. This consequently leads to disability being viewed as a dichotomous outcome (such as, people are either disabled or they are not) and, in turn, leads to significant underestimates of the prevalence of disability whereby the stigma of disability or the reporting of only visible disabilities affects the reporting and recording of disabilities (Cappa et al., 2015; Loeb et al., 2018). A further critique of the medical model is that it is seen to reduce disabled people to passive recipients of care, charity and philanthropy rather than recognising disabled people as holders of rights and agency (Brady and Franklin, 2023).

The social model of disability highlights the disabling effects of structural, social and attitudinal barriers on disabled people's lives as separate from the individual experiences of, for example, physical or sensory impairments (Brady and Franklin, 2023). Disability here is consequently understood and felt as the result of the interaction between disabled people and the attitudes and environmental barriers that hinder their full and effective participation in society on an equal basis with others (Cappa et al., 2015; Colver 2005). From a measurement perspective, the social model of disability encourages us to ask what people have difficulty doing (such as difficulty seeing, walking or learning things), as opposed to asking what condition or impairment a person may have. This is a more inclusive and less stigmatising means of capturing all types of disability and enables some disaggregation of different types and severity of disability (Cappa et al., 2015).

The human rights model of disability is put forward by the UNCRPD and notes that disability is a natural part of human diversity that must be respected and supported in all its forms; disabled people have the same rights as everyone else in society; and impairment must not be used as an excuse to deny or restrict people's rights. The model therefore encompasses the need for the equality, non-discrimination, and full inclusion and participation of disabled people. From a measurement perspective, the UNCRPD's definition of disability encourages statistical collections that capture both the presence of an impairment and whether adjustments have been made so that the individual can fully participate in society.

Box 3: UNCRPD definition of disability (Article 1 and repeated in UNCRC General Comment No. 9)

"Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."

Difficulties in collecting statistics

There is a clear international policy directive and intention around the need to collect accurate statistics on disabled children (Crialesi et al., 2016; UNCRPD, 2006). However, and despite several initiatives to measure and collect disability statistics among adults (for example, the Washington Group on Disability Statistics, European Health and Social Integration Survey, the Budapest Open Access Initiative, and the World Health Organization's Disability Assessment schedule), there have been few endeavours to collect equivalent information for children and young people (Meltzer, 2016).

There are many reasons behind the limited collection and availability of statistics concerning disabled children, including:

- Conceptual difficulties and differences in defining disability:
 - Disability is more difficult to define for children (and especially younger children) compared to adults (Meltzer, 2016). Distinguishing between a disability, an age and stage developmental delay, and an impact of

trauma can be difficult, particularly for neurodiverse children (Legano et al., 2021).

- Children are in a constant state of development (Crales et al., 2016; Loeb et al., 2018). The continuous change in their abilities to perform actions and activities makes the measurement of disability fluid.
- "*Disability is not an all or nothing phenomenon, rather it represents a continuum from none to very severe difficulty*" (Crales et al., 2016 pp163). This poses the question: at what point along the continuum should disability be recorded?
- Different countries and cultures define and conceptualise disability differently, which makes it challenging to arrive at consistent international measures (Cappa et al., 2015; Crales et al., 2016; Loeb et al., 2018; Meltzer, 2016).
- The responsibility for disabled children (and the collection of statistics concerning disabled children) falls across multiple government departments and partner organisations, including health, education, social work and third sector organisations. Considerable co-ordination and political commitment is therefore required to launch a national survey concerning disabled children (Meltzer, 2016).
- Practitioners have differing levels of confidence and competence in identifying and assessing for disabilities.
- Methodological and ethical challenges in collecting self-declared disability data from parents, carers or children. For example, they might not identify their child and/or themselves as being disabled or with the models and categories of disability used within statistical collections. The UNCRC General Comment No. 9 notes that, "*Extra efforts are often needed to collect data on children with disabilities because they are often hidden by their parents or others caring for the child*" (para 19).

Combined, these factors contribute to an underestimate and under-recording of the prevalence of disability and means that the individual and collective needs of disabled children are neither fully visible nor fully understood among politicians, senior leaders and practitioners (Cappa et al., 2015; Loeb et al., 2018; Stalker and McArthur, 2012).

This lack of visibility is particularly important to address given that disabled children have been found to be at greater risk of harm and abuse than non-disabled children. Two widely quoted studies are Jones et al.'s (2012) meta-analysis of 17 US and European studies which found that disabled children have experienced harm and abuse three to four times more than non-disabled children, and Sullivan and Knutson (2000) which found that disabled children living in Nebraska (United States) had experienced physical abuse three to four more times than children who were not disabled. Factors which have been identified as contributing to disabled children's increased risk of harm and abuse include the increased levels of parental or carer social isolation, financial hardship and stress in meeting their child's care and support needs; the sexual, criminal or online exploitation of disabled children; and practitioners and services not identifying or responding to protection concerns impacting on disabled children (Franklin et al., 2022; Stalker and McArthur, 2012).

Disabled children being this much more at risk of harm and abuse is a stark statistic. This statistic is however "*considered to be an underestimation, given the lack of attention placed on disabled child abuse, and due to the fact that disabled children are often invisible, marginalised, not listened to or heard*" (Franklin et al., 2020 pp65). It also hides different levels of risk within the disabled children population. For example, studies indicate that disabled children's risk of harm and abuse varies according to their type of impairment, with having a mental or learning disability, communication impairment or behavioural difficulty being more strongly associated with maltreatment (Jones et al., 2012; Legano et al., 2021; Sullivan and Knutson, 2000). The different levels of risk highlight the importance of collecting statistics for different groupings of disabled children, as well as for disabled children as a whole.

Key summary points

- Disabled children are at increased risk of harm and abuse. To understand more fully their risks and their experiences, and to help ensure their rights and needs are met, there is a need to collect good quality statistics.
- Collecting disabled children's statistical data is not, however, an easy task. There are different definitions of disability, varying levels of practitioner confidence in identifying and assessing disability, and questions about whether and how to include child, parent or carer declaration of disability.
- A clear and widely agreed definition of disability is required that can be consistently used for local, regional, national and (ideally) international statistical collections. The policy and academic literature advocates moving beyond the medical model of disability to a definition and statistical collection that aligns with the social and human rights models of disability.
- Given that studies indicate the risk of harm and abuse varies according to type of impairment, there is also a need for statistical definitions and collections that enable the needs, risks and experiences of different groupings of disabled children to be captured.

3. International data on disabled children

The main source of international data on disabled children comes from the [Washington Group/UNICEF Module on Child Functioning](#). Consistent with the social and human rights models of disability, the Module has been developed to capture data on the presence and extent of functional difficulties of children aged 2-17 years. Data is therefore captured on a wide range of difficulties, including physical, communication, behavioural, relationship and mental health difficulties, as opposed to data specifically tied to children’s medical conditions or impairments.

Figure 1 summarises the functional difficulties asked about, noting that the Module comprises two questionnaires (one for children aged 2 to 4 years and one for children aged 5 to 17 years) and, where possible, each question asked has a rating scale of ‘no difficulty’, ‘some difficulty’, ‘a lot of difficulty’, and ‘cannot do at all’ to reflect the degree of functional difficulty. The questionnaires are completed by parents or primary carers via national household surveys and censuses. By using national surveys, the questionnaires provide population-level estimates of the number and proportion of children with functional difficulties.

Figure 1: Functional Difficulties in the Module on Child Functioning (2-4 year old questionnaire and 5-17 year old questionnaire)

Functional Difficulty	Examples of functional difficulties given in questionnaires	2-4 years	5-17 years
Seeing	Difficulty seeing	Yes	Yes
Hearing	Difficulty hearing sounds like people’s voices or music	Yes	Yes
Mobility	Difficulty walking	Yes	Yes
Fine Motor	Difficulty picking up small objects	Yes	
Communication/ comprehension	Difficulty understanding or being understood	Yes	Yes
Controlling behaviour	Kicking, biting or hitting other children or adults (2-4 years); difficulty with controlling their behaviour (5-17 years)	Yes	Yes
Learning	Difficulty learning things	Yes	Yes
Playing	Difficulty playing	Yes	
Self-care	Difficulty with feeding or dressing		Yes
Remembering	Difficulty remembering things		Yes
Attention and concentrating	Difficulty concentrating on an activity they enjoy doing		Yes
Relationships	Difficulty making friends		Yes
Anxiety	Very anxious, nervous or worried on a <u>daily</u> basis*		Yes
Depression	Very sad or depressed on a <u>daily</u> basis*		Yes

Source: UNICEF (2021) Seen, Counted, Included

* Children aged 5–17 years who have daily (as opposed to weekly or less frequent) episodes of anxiety or depression are considered to have a functional difficulty

Across 103 countries, data from the Child Functioning Module questionnaires and other comparable national data sources were brought together in the UNICEF (2021) report [Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities](#). Its key findings included:

- Across the data, 10% of children aged 0 to 17 years had a functional difficulty.
- By age group:
 - 5% of children aged 2 to 4 years had one or more functional difficulties.
 - 16% of children aged 5 to 17 years had one or more functional difficulties.
- By global region:
 - West and Central Africa had the highest percentage of children with one or more functional difficulties at 15%.
 - Europe and Central Asia had the lowest percentage at 6%. Data was not available for Europe alone.
- By functional domain, the domains that most affected children were:
 - For 2 to 4 year olds: controlling behaviour (2%), learning (2%), and communication (2%).
 - For 5 to 17 year olds: anxiety (7%), depression (4%), and controlling behaviour (4%).

Key summary points

- The Washington Group/UNICEF Module on Child Functioning adopts the social model of disability and focuses on measuring functional difficulties.
- Using this module, the UNICEF (2021) report '*Seen, Counted, Included*' found that 10% of the world's children had functional difficulties. In Europe and Central Asia, the proportion was 6% of children.
- Levels of functional difficulties were found to be higher among 5-17 year olds (16% of children) than 2-4 year olds (5% of children), which indicates that disability is more prevalent and/or more readily identified among older children.

4. Scotland data on disabled children

In Scotland, guidance concerning the collection of disabled people's statistics is provided by the Scottish Government (2022) [Data collection and publication guidance: Disability](#). Developed by the Scottish Government, the UK's Office for National Statistics and the UK's Office for Disability Issues, the guidance offers a harmonised suite of questions on disability for use in surveys in Scotland, with the aim of enhancing Scotland's collection of statistics concerning disabled people.

Using the UK's Equality Act 2010 definition that "*a person has a disability if they have a physical or mental impairment, and the impairment has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities*", the guidance provides a set of recommended questions that can be used in Scottish statistical collections (Box 4). A person is recorded as disabled where a person answers 'Yes' to Question A and either 'Yes, a lot' or 'Yes, a little' to Question C.

Box 4: Disability-related questions posed in Scottish Government (2022) Data collection and publication guidance: Disability

Question A: Do you have any physical or mental health conditions or illnesses lasting or expected to last 12 months or more?

1. Yes
2. No
3. Don't know
4. Refusal
5. Prefer not to say

If answer 'Yes' to Question A:

Question B: Do any of these conditions or illnesses affect you in any of the following areas?

1. Vision (for example blindness or partial sight)
2. Hearing (for example deafness or partial hearing)
3. Mobility (for example walking short distances or climbing stairs)
4. Dexterity (for example lifting or carrying objects, using a keyboard)
5. Learning or understanding or concentrating
6. Memory
7. Mental health
8. Stamina or breathing or fatigue
9. Socially or behaviourally (for example, associated with autism spectrum disorder (ASD) which includes Asperger's Syndrome, or attention deficit hyperactivity disorder (ADHD))
10. Other (please specify)
11. None of the above
12. Refusal
13. Prefer not to say

If answer 'Yes' to Question B:

Question C: Does your condition or illness/do any of your conditions or illnesses reduce your ability to carry-out day-to-day activities?

1. Yes, a lot
2. Yes, a little
3. Not at all
4. Refusal
5. Prefer not to say

Normal day-to-day activities can include: washing and dressing, household cleaning, cooking, shopping for essentials, using public or private transport, walking a defined distance, climbing stairs, remembering to pay bills, lifting objects from the ground or a work surface in the kitchen, moderate manual tasks such as gardening, gripping objects such as cutlery, and hearing and speaking in a noisy room.

Having a harmonised set of questions should enable a more consistent approach to the collection of statistics concerning disabled people but there are some issues to consider:

- While the guidance states that the Scottish Government is committed to the social model of disability, it reports that there are currently no tried and tested questions in use in official surveys that reflect the social model of disability (the guidance makes no mention of the Washington Group/UNICEF Module on Child Functioning). The guidance therefore acknowledges that the set of questions are most closely tied to a medical model of disability, but that work to provide a harmonised set of questions in line with the social model of disability is ongoing.
- Although developed without reference to the Washington Group/UNICEF Module on Child Functioning, the nine Question B 'conditions' or 'illnesses' do align closely with the functional difficulties asked in the Washington Group/UNICEF Module on Child Functioning, albeit communication, self-care, playing and relationships are not asked about.
- The questions are not specifically tailored to children, for example, the normal day-to-day activities referred to in Question C are predominantly activities undertaken by adults.

Notwithstanding the need for some further development work, the guidance does appear to offer a consistent way of collecting statistics about disabled adults and children that aligns with international definitions and collections. However, the guidance is not currently being used across Scotland's children's data collections, which raises questions around its status, dissemination and implementation.

All Children

The most comprehensive source of data for all children in Scotland is the national census conducted every 10 years. Box 5 sets out the disability-related questions used in the 2022 Scotland Census, with these differing from the Scottish Government (2022) [Data collection and publication guidance: Disability](#) questions shown in Box 4.

Box 5: Disability-related questions posed in 2022 Census

Question A: Do you have any of the following, which have lasted, or are expected to last, at least 12 months?

- Deafness or partial hearing loss.
- Blindness or partial sight loss.
- Full or partial loss of voice or difficulty speaking (a condition that requires you to use equipment to speak).
- Learning disability (a condition that you have had since childhood that affects the way you learn, understand information and communicate).
- Learning difficulty (a specific learning condition that affects the way you learn and process information).
- Developmental disorder (a condition that you have had since childhood which affects motor, cognitive, social and emotional skills, and speech and language).
- Physical disability (a condition that substantially limits one or more basic physical activities such as walking, climbing stairs, lifting or carrying).
- Mental health condition (a condition that affects your emotional, physical and mental wellbeing).
- Long-term illness, disease or condition (a condition, not listed above, that you may have for life, which may be managed with treatment or medication).
- Other condition (please write in).
- No condition.

If answer 'Yes' to Question B:

Question B: Are your day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months? (including problems related to old age)

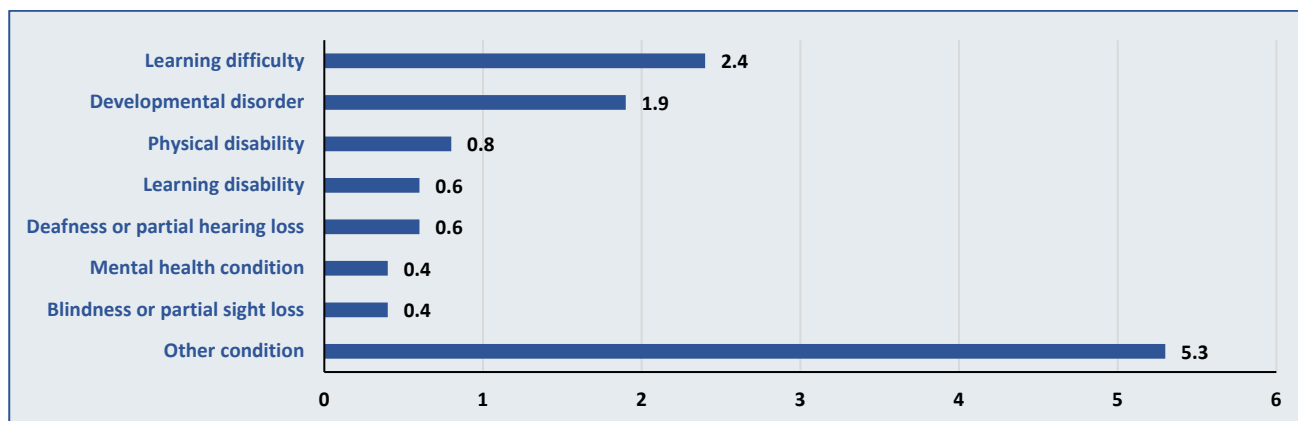
- Yes, limited a lot.
- Yes, limited a little.

The 2022 Scotland Census findings from the disability-related questions have not yet been published. The [2011 Census](#) findings distinguished between disabled children and children with a long-term health condition and found:

- 4.8% of children were reported as disabled, with this figure broken down as:
 - 1.7% of 0-15 year olds were reported as having their day-to-day activities limited a lot by their disability.
 - 3.1% of 0-15 year olds were reported as having their day-to-day activities limited a little by their disability.
- 10.7% of children were reported as having long-term health conditions.

Figure 2 shows the available breakdown of the data for different long-term health conditions but no documentation could be found that clarified which categories are grouped as a disability (i.e. make up the 4.8% of children reported as disabled), which were grouped as a long-term health condition (i.e. make up the 10.7% of children reported to have long-term health conditions), and what has been recorded under 'other condition'.

Figure 2: 0-15 year olds by Long-Term Health Condition (% of all children), Scotland, 2011



Source: Scotland's Census 2011

Note: Multiple forms of disability can be recorded

A more up-to-date source of data relating to children with a limiting long-term illness is the [Scottish Health Survey](#). For 2022, it found that 15% of children had a limiting long-term illness. The Scottish Health Survey does not have a question specifically related to disability.

Early Years

Universal Health Visiting Pathway

There are two early years children's data publications that include data which relates to disability in Scotland. The first is data that comes from the Universal Health Visitor Pathway reviews, with Public Health Scotland publishing [Early Child Development](#) data for the 13-15 month, 27-30 month and 4-5 year (pre-school) reviews. Using the Ages & Stages Questionnaires, 'disability' is not a specific assessment aspect and therefore there is not a 'disability' field in the data collection form completed by health visitors. Instead, and with apparent alignment to the social model of disability, there is an assessment and recording of age and stage appropriate everyday movements, activities and behaviours in order to observe for the child having any developmental concerns. These developmental concerns are then grouped into eight 'domains':

- Speech, language and communication development
- Emotional/behavioural development
- Personal/social development
- Fine motor development
- Gross motor development
- Vision
- Hearing
- Problem-solving development

Data is published separately for each of the eight domains but caution must be taken in classifying one or more of the domains as 'disability domains', and others not. As a consequence, the data presented is the percentage of children with a concern in any developmental domain. For 2022/23, Public Health Scotland's Early Child Development data shows that:

- 12.5% of 13-15 month olds reviewed had a developmental concern
- 17.9% of 27-30 month olds reviewed had a developmental concern
- 16.6% of 4-5 year olds reviewed had a developmental concern.

Collectively the data suggests that developmental concerns were identified for between 12% and 18% of Scotland's infants in 2022/23.

Early Learning and Childcare

The second early years data publication is the Scottish Government's [Early Learning and Childcare Census](#). In contrast to the Scottish Government (2022) *Data collection and publication guidance: Disability* and the *Washington Group/UNICEF Module on Child Functioning* which ask questions about disability only, the Early Learning and Childcare Census collects data for children assessed and/or declared as disabled, and for children with additional support needs.

For the children assessed and/or declared as disabled, the [Early Learning and Childcare Census Guidance](#) uses the Equality Act 2010 definition of disability, and makes the distinction between disability being 'assessed' and 'declared'.

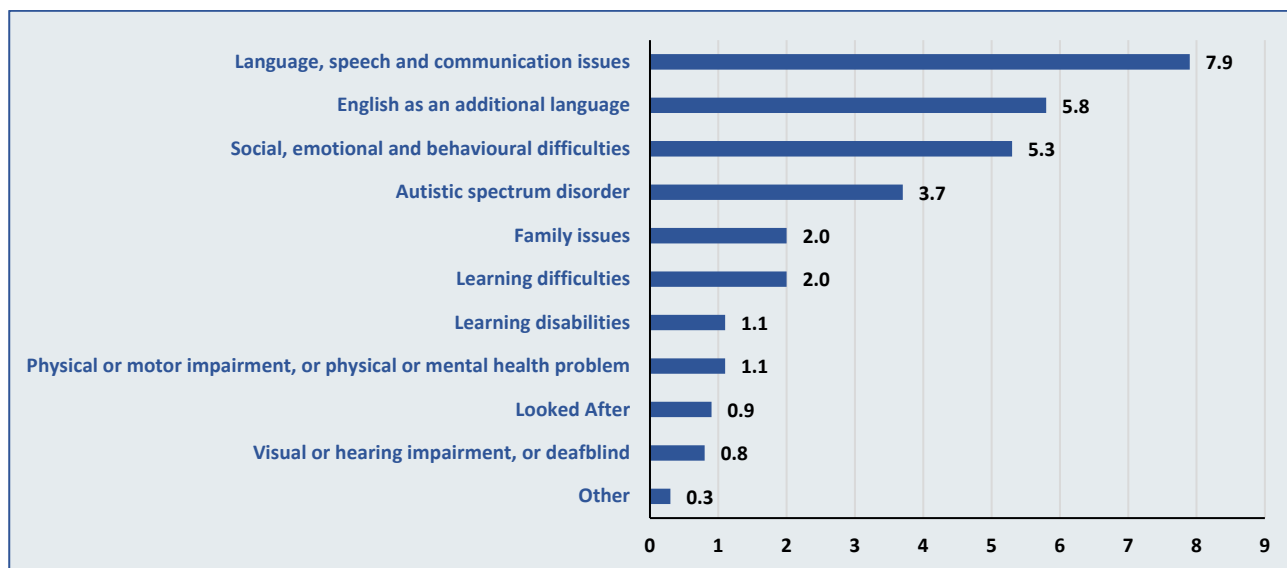
- 'Assessed as disabled' is when disability is stated by a qualified professional (for example, 'an appropriate health professional, educational psychologist, or similar') irrespective of whether the child or parent has declared them as disabled.
- 'Declared as disabled' is when disability is stated by the child or parent, irrespective of whether the declaration has been confirmed by a professional assessment.

The Early Learning and Childcare Census publication brings together the assessed and/or declared as disabled into one measure and reported that in 2023, 1.8% of children registered with Early Learning and Childcare centres in Scotland were disabled.

The second measure is the number of children with additional support needs, which encompasses 10 sub-categories (Figure 3). The 2023 data finds that:

- 18.4% of children registered with Early Learning and Childcare centres had additional support needs.
- By sub-category, the main additional support needs were language, speech and communication issues; English as an additional language; and social, emotional and behavioural difficulties.

Figure 3: Children registered with Early Learning and Childcare centres by Additional Support Needs (% of children, 2023)



Source: Scottish Government Additional Early Learning and Childcare tables, 2023

A number of the additional support needs sub-categories could potentially be regrouped under a wider measure of disability. For example, autistic spectrum disorder (3.7%); language, speech and communication issues (7.9%); learning difficulties (2.0%); learning disabilities (1.1%); physical or motor impairment, or physical or mental health problem (1.1%); social, emotional and behavioural difficulties (5.3%); and visual or hearing impairment, or deafblind (0.8%) could constitute a redrawn measure of disability that is consistent with the Scottish Government (2022) *Data collection and publication guidance: Disability* and the *Washington Group/UNICEF Module on Child Functioning*. If this was agreed to, and with the caveat that children may have multiple additional support needs, up to a further 15% of children could be categorised as disabled. This percentage would be consistent with the Universal Health Visitor Pathway data indicating that 12% to 18% of Scotland’s infants have developmental concerns.

School Education

Like the Early Learning and Childcare Census, the Scottish Government’s [Pupil Census](#) of primary and secondary school pupils collects and reports data separately for disability and additional support needs. Pupils are recorded as disabled if they need ‘access to physical adaptation’, ‘access to curriculum adaptation’ and/or ‘access to communication adaptation’ to attend and participate in school. Using these declarations, the data from the 2022/23 Pupil Census shows:

- 1.8% of primary school pupils were assessed or declared as disabled.
- 3.3% of secondary school pupils were assessed or declared as disabled.
- 3.1% of all school pupils were assessed or declared as disabled.

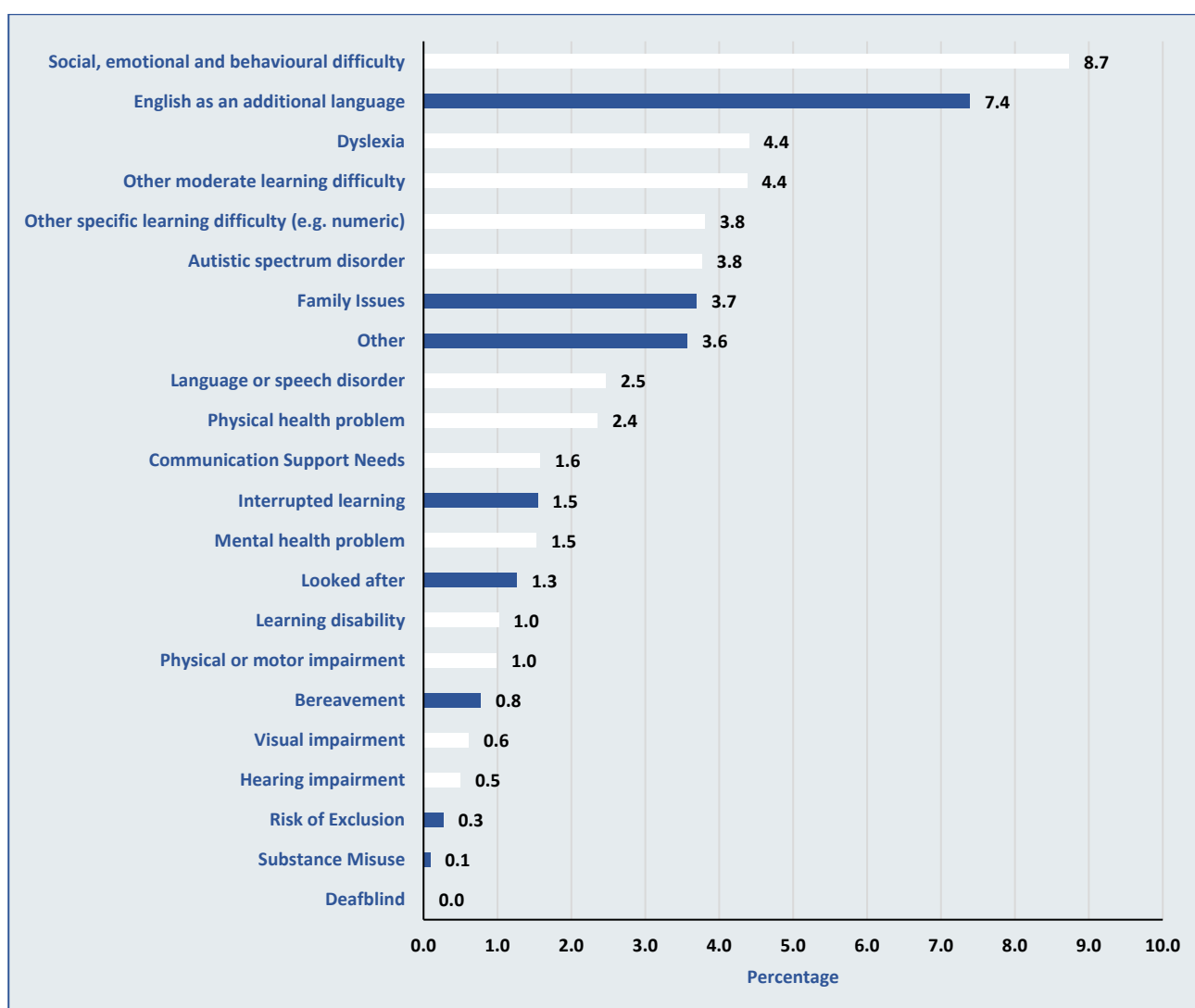
Pupils are recorded as having an additional support need if, in line with the [Education \(Additional Support for Learning\) Scotland Act 2004](#), they need additional support in order to overcome barriers and benefit from school education. Most children with additional support needs are educated in mainstream schools, but some pupils with

complex or specific needs are educated in special schools. The 2022/23 data presented here is for pupils in mainstream schools, and this data may include pupils who attend a 'special unit' attached to a mainstream school:

- 30.4% of primary school pupils in mainstream schools had additional support needs.
- 42.9% of secondary school pupils in mainstream schools had additional support needs.
- 36.0% of all school pupils in mainstream schools had additional support needs.

Additional support needs encompass a wide range of needs (Figure 4) and many of these could conceivably be included within a wider measure of disability. If they were, as can be seen by the bars marked in white in Figure 4, the proportion of pupils with a disability would substantially exceed the figure of 3.1% given in the Pupil Census.

Figure 4: % of Primary and Secondary School Pupils by Additional Support Need, Scotland 2022-23



Source: Scottish Government Pupil Census, 2022/23

Note: White bars used by author to highlight which additional support needs options could be included within a wider definition of disability

Young People

Further and Higher Education

Under the Widening Access policy priority in Scotland, the [Scottish Funding Council Report on Widening Access 2021-22](#) reported a much higher level of disability among Scotland's young people than the levels reported among Scotland's school pupils. Reasons for this include colleges and universities asking about disability and additional support needs in a combined question; the question using self-reported data from students; and disability and additional support needs being more prevalent among older children and young people.

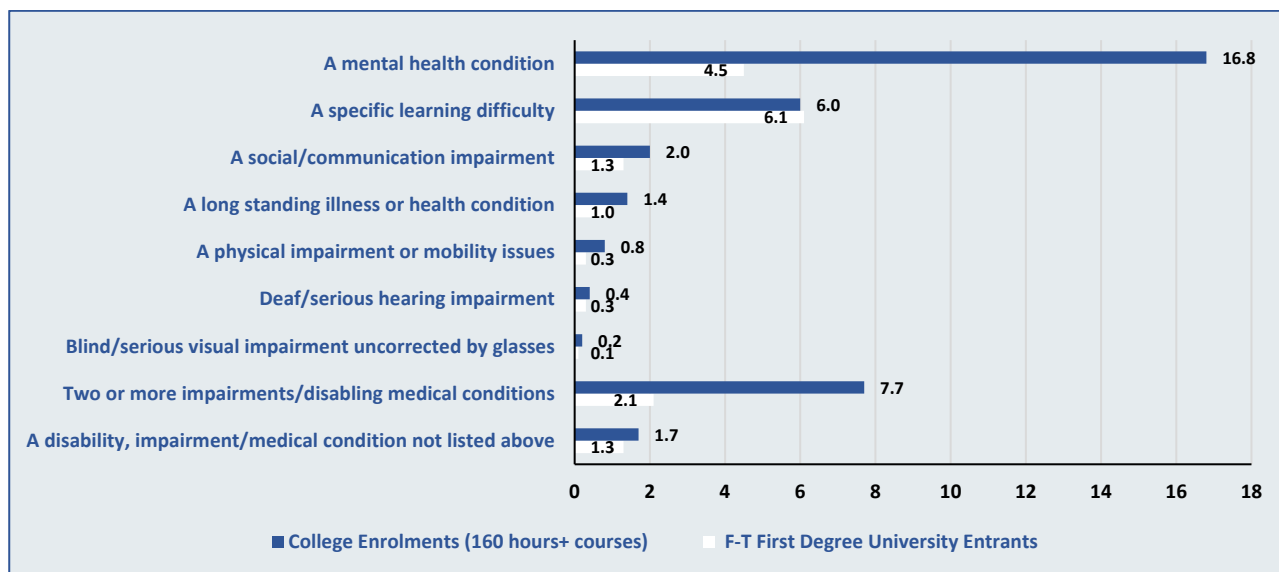
The data shows:

- In the college sector:
 - 21.2% of enrolments to full-time HE level college courses were by students with a declared disability.
 - 29.9% of enrolments to full-time FE level college courses were from students with a declared disability.
- For universities, 17.4% of Scottish-domiciled entrants to full-time first-degree courses at university with a declared disability.

Figure 5 provides a breakdown by type of disability for the categories recorded by colleges and universities, with mental health conditions and learning difficulties the most prevalent categories. The categories are shown in Figure 5 under shortened titles. Their full disability titles, giving examples of the specific conditions in each group, are:

- A mental health condition, such as depression, schizophrenia or anxiety disorder.
- A specific learning difficulty, such as dyslexia, dyspraxia or AD(H)D.
- A social/communication impairment, such as Asperger's syndrome/other autistic spectrum disorder.
- A long-standing illness or health condition such as cancer, HIV, diabetes, chronic heart disease, or epilepsy.
- A physical impairment or mobility issues, such as difficulty using arms or using a wheelchair or crutches.
- Deaf or a serious hearing impairment.
- Blind or a serious visual impairment uncorrected by glasses.
- A disability, impairment or medical condition that is not listed above.
- Two or more impairments and/or disabling medical conditions.

Figure 5: % of College and University Scottish-Domiciled Student Enrolments with a declared disability, 2021-22



Source: Scottish Funding Council Report on Widening Access 2021-22

Apprenticeships

All young people starting a Modern Apprenticeship in Scotland are asked to complete an equality monitoring form. The Disability Monitoring Questions that Skills Development Scotland use for this are set out in Box 6. The questions were introduced in 2016/17 and align with the wording recommended by Advance HE (formerly the Equality Challenge Unit) after extensive consultation with disability partners, Modern Apprentices, learning providers and employers. In response to the questions, 15.3% of young people starting a Modern Apprenticeship self-reported that they had an 'impairment, health condition or learning difficulty' in 2022/23.

Box 6: Disability-related questions posed in Skills Development Scotland's Disability Monitoring Question for Modern Apprentices

Question A: Do you have an impairment, health condition or learning difficulty (lasting or expected to last 12 months or more)?

- Yes
- No
- Prefer not to say

Question B: If you have an impairment, health condition or learning difficulty, please select all those on the list that apply.

- You have a social/communication impairment such as a speech and language impairment or Asperger's syndrome/other autistic spectrum disorder
- You have a learning disability (a condition that you have had since childhood that affects the way you learn, understand information and communicate) such as Down's Syndrome
- You are blind or have a visual impairment uncorrected by glasses
- You are deaf or have a hearing impairment
- You have a long-standing illness or health condition such as cancer, HIV, diabetes, chronic heart disease, or epilepsy

- You have a mental health difficulty, such as depression, schizophrenia or anxiety disorder
- You have a specific learning difficulty such as dyslexia, dyspraxia or AD(H)D
- You have a physical impairment or mobility issues, such as difficulty using your arms or using a wheelchair or crutches
- You have a disability, impairment or medical condition that is not listed above
- Prefer not to say

Other sources of disabled children's data

There are other sources of data which report on disabled children specifically as opposed to the children population as a whole. For example:

- Public Health Scotland [Insights in social care: statistics for Scotland](#) reported that 1,320 children were receiving Self-Directed Support in 2021/22.
- Social Security Scotland [Child Disability Payment statistics](#) reported that 75,935 children in December 2023 were in receipt of the Child Disability Payment, which equates to 7.4% of Scotland's 1,025,000 children receiving the Child Disability Payment. Table 18 of that statistical release provides a breakdown of children's 'primary disability condition' and these indicate that a medical model of disability has been taken here. The most prevalent conditions recorded were:
 - Mental and behavioural disorders: 56,815 children or 75% of recipients. A further breakdown reports that 30,585 were children with autism, 8,940 were children with ADHD, and 17,285 were children with other mental and behavioural disorders.
 - Endocrine, nutritional and metabolic diseases: 3,520 children or 5% of recipients.
 - Diseases of the nervous system: 3,015 children or 4% of recipients.
 - Congenital malformations, deformations and chromosomal abnormalities: 2,450 children or 3% of children.

These two sources provide further examples of the Scottish Government (2022) guidance not being used consistently in different statistical collections.

Key summary points

- The Scottish Government has produced guidance to support the consistent collection of disability statistics. However, the guidance is not yet being used in all of Scotland's children's statistical collections and instead there is notable variation in how disability is asked about.
- Some collections ask about disability and additional support needs separately, and these collections report a low level of disability but a high level of additional support need. For example:
 - In early learning and childcare, 1.8% of children were reported as disabled in 2022 and 18.4% had additional support needs.
 - In schools, 3% of pupils in mainstream schools were assessed or declared as disabled, and 36% of pupils had additional support needs.

- Other collections used a question that combined disability, additional support needs and/or developmental needs, and these reported a higher level of disability. For example:
 - Universal Health Visitor Pathway data shows developmental concerns were identified for between 12% and 18% of Scotland's infants in 2021/22.
 - College, university and apprenticeship data for Scotland's young people reported that between 15% and 30% of students or apprentices were disabled.

5. Data on disabled children in need of care and protection

Like all children in Scotland, some disabled children are in need of care and protection and they will be supported by child protection processes and/or may become 'looked after' under the [Children \(Scotland\) Act 1995](#) and cared for by others including foster carers or specialist services including residential care if their parents are unable to provide the care they need. Having good quality statistics about disabled children who are in need of care and protection is particularly important because disabled children are at an increased risk of harm and abuse than non-disabled children (Cappa et al., 2015; Franklin et al., 2020; 2022; Jones et al., 2012; Loeb et al., 2018; Stalker and McArthur, 2012; Sullivan and Knutson, 2000).

Scotland data

The key source of data is the Scottish Government's annual [Children's Social Work Statistics](#) which uses the Equality Act 2010 definition of disability to support the identification and recording of disabled children. Further clarifications to the Equality Act 2010 definition are then provided in the guidance notes for the practitioners responsible for collecting and reporting this data:

- Mental or physical impairment with a substantial adverse effect means significant difficulties with any of:
 - mobility, lifting/carrying;
 - manual dexterity;
 - continence;
 - communication (speech, hearing, eyesight);
 - memory/ability to concentrate or understand;
 - recognise if in physical danger;
 - physical co-ordination;
 - other problem or disability that you think has an adverse effect on their ability to carry out normal day-to-day activities.
- Long-term means 12 months or more. For children under a year, 'long-term' should be assessed in relation to their age.

Parental declaration of disability is not used, with a child's disability assessed and recorded by a practitioner.

The annual published Children's Social Work Statistics report provides disability data for children registered on the Child Protection Register, starting to be 'looked after', 'looked after', ceasing to be 'looked after', admitted to secure care, and eligible for aftercare services. The data for 2022/23 shows:

- Child protection:
 - 5.1% of the 2,094 children on the child protection register on 31 July 2023 were assessed as having a disability; but a further 37.2% of children did not have their disability assessed, recorded or known.
- 'Looked after' children:
 - 9.6% of the 12,206 'looked after' children in Scotland on 31 July 2023 were assessed as having a disability; but a further 24.4% of children did not have their disability assessed, recorded or known.

- 7.2% of the 3,004 children starting to be 'looked after' during that year were assessed as having a disability; but a further 29.7% of children did not have their disability assessed, recorded or known.
- 9.3% of 3,286 children ceasing to be 'looked after' children during that year were assessed as having a disability; but a further 24.8% of children did not have their disability assessed, recorded or known.
- Children admitted to secure care:
 - 29.2% of 154 children admitted to secure care in 2022/23 were recorded as disabled.
- Young people eligible for aftercare services:
 - 14.7% of 8,517 young people eligible for aftercare in 2022/23 were recorded as disabled; but a further 20.6% of young people did not have their disability assessed, recorded or known.

Further detail on the 'looked after' children assessed as having a disability is provided by additional analysis from the Scottish Government of the 2021-22 data, generated for this review, which finds that levels of disability were higher for children living in residential care settings. Figure 6 shows that one quarter (26%) of children living in residential care were recorded as disabled, with the highest proportion (40% of children) being cared for and learning in residential schools.

Figure 6: 'Looked After' Children by Place of Residence and Levels of Disability for those children (%), 31 July 2022

	% of all looked after children by place of residence	% of children in each place of residence recorded as disabled
At Home	20.9%	6.6%
In Kinship care	33.7%	5.9%
In Foster care	33.0%	10.7%
In residential setting	10.2%	26.0%
- Local authority home	4.5%	18.1%
- Voluntary home	6.4%	21.3%
- Residential school	2.5%	40.0%
- Secure accommodation	0.4%	22.9%
All 'looked after' children	100.0%	9.7%

Source: Bespoke analysis provided by Scottish Government for this review of the data

The additional support needs of children in need of care and protection are not collected as part of this dataset, but this information was collected prior to the 2015/16 annual Children's Social Work Statistics collection (Box 6). Since then this has been replaced with a binary Yes/No indicator of whether "A person is disabled if the child/young person has a mental or physical impairment which has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities".

Another key source of data about children in need of care and protection is the Scottish Children's Reporter Administration (SCRA) because it collects data about

children referred to the Children's Hearing System. As explained in Box 7, it is developing the way it records disability data.

Box 7: Disability recording by the Scottish Children's Reporter Administration

SCRA's current improvement work in relation to keeping The Promise has a focus on data recording. SCRA's child-friendly scheduling, commitment standards and Taking Control of My Hearing projects aim to improve the approach to meeting children's needs around scheduling of and participation in hearings. The projects are developing and testing ways of gathering relevant information to inform effective hearing arrangement, including data on protected characteristics.

Disability has previously been recorded in a 'yes/no/don't know' field but levels and quality of completion varied. As a consequence, disability statistics have not to date been published. SCRA's current data and case management system, CSAS (launched throughout 2020), has functionality which allows users to multi-select disability across the following:

- Blindness or partial sight loss.
- Deafness or partial hearing loss.
- Developmental disorder.
- Learning difficulty.
- Learning disability.
- Long term illness, disease or condition.
- Mental health condition.
- Physical disability.
- Other condition (please specify).

Alongside these there are also free text recording options. A consistent way of working across these recording categories will need to be developed. This new functionality should result in SCRA developing a reporting approach across this area of work and result in improvements to the way in which SCRA work with children and families as they engage with the Children's Hearings System.

SCRA aims to have robust equality data for children within 5 years which will help SCRA to provide a relational, needs based approach and to develop and target its resources effectively.

Other challenges encountered in the recording of disability include:

- How to record multiple types of disability for a child or young person.
- How to ask children, parents/carers and/or partner agencies for additional information where it is missing.
- How to record changes in a child's disability over time.

Disability is assessed/observed as part of SCRA research studies. These studies involve qualitative analysis of children and young people's full case files and this detailed lens offers a more accurate picture of disability levels. For example:

- SCRA (2016) *Backgrounds and outcomes for children aged 8 to 11 years old who have been referred to the Children's Reporter for offending* found that

13% of the 100 children sample were recorded as having a disability, but a further 26% had physical and/or mental health concerns.

- SCRA (2017) *16 and 17 year olds in the Children's Hearings System* found that 13% of the 113 sample were assessed as having a disability.
- SCRA (2019) *Compulsory Supervision Orders Report 1 – Residence and contact conditions* found that 10% of the 343 children and young people sample had a disability.
- SCRA (2020) *Sexual exploitation of children involved in the Children's Hearings System* found that 16% of 74 children who were victims or likely victims of CSE had a disability and 30% had a learning difficulty.

For SCRA, the benefits of more accurate recording of children and young people's disability were reported to be two-fold:

- From a research perspective, the data will provide greater understanding of any relationships between (types of) disability and harm and abuse.
- From a service provider perspective, the data will enable SCRA to better meet the needs of disabled children and young people by taking their needs into account in the hearing arrangements.

SCRA recognises the limitations of the medical model of disability and are aiming to record disability in a manner consistent with the social model. In doing so, SCRA hopes that the artificial divide between 'disability' and 'additional support needs' can be overcome.

Data for other UK nations

As context for the picture in Scotland, data for the other three nations of the UK has been looked at. This includes data from the latest population censuses and data about disabled children in need of care and protection that is collected in the [Children in Need Census](#) in England, the [Children Receiving Care and Support Census](#) in Wales, and [Children's Social Care Statistics](#) in Northern Ireland.

England

England's 2021 Census findings record that 6.3% of children aged 0-15 were reported as disabled, with this breaking down as:

- 2.5% of 0-15 year olds were reported as having their day-to-day activities limited a lot by their disability.
- 3.7% of 0-15 year olds were reported as having their day-to-day activities limited a little by their disability.

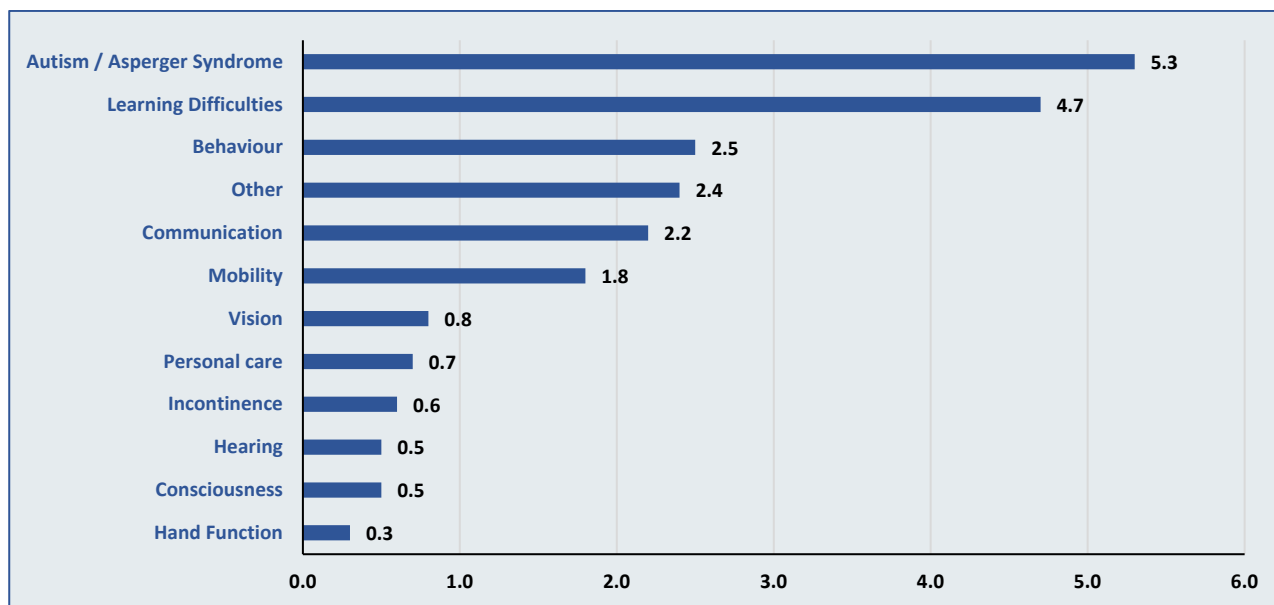
The annual [Children in Need Census](#), run by the Department for Education in England, captures the number and characteristics of children assessed as needing help and protection as a result of risks to their development or health (in line with the Children Act 1989). 'Children in need' includes children for whom there is a Child in Need Plan or a Child Protection Plan, 'looked after' children, young carers, and disabled children.

Disability within this census is defined under the UK's [Disability Discrimination Act 2005](#), that is, a disabled person is a person with a "physical or mental impairment

which has a substantial and long-term adverse effect on his or her ability to carry out normal day to day activities." The condition must have lasted or be likely to last at least 12 months to be classed as a disability. Using this definition, of the 403,090 children in need on 31 March 2023, 12.8% had a recorded disability.

The Children in Need Census also provides a breakdown by type of disability and shows a wide range of disabilities/difficulties are recorded. Autism/Asperger Syndrome and learning difficulties were the most widely recorded categories.

Figure 7: Children in Need with a Recorded Disability by Category, 2023, England (% of all children in need)



Source: Children in Need Census 2023

Note: Multiple forms of disability can be recorded

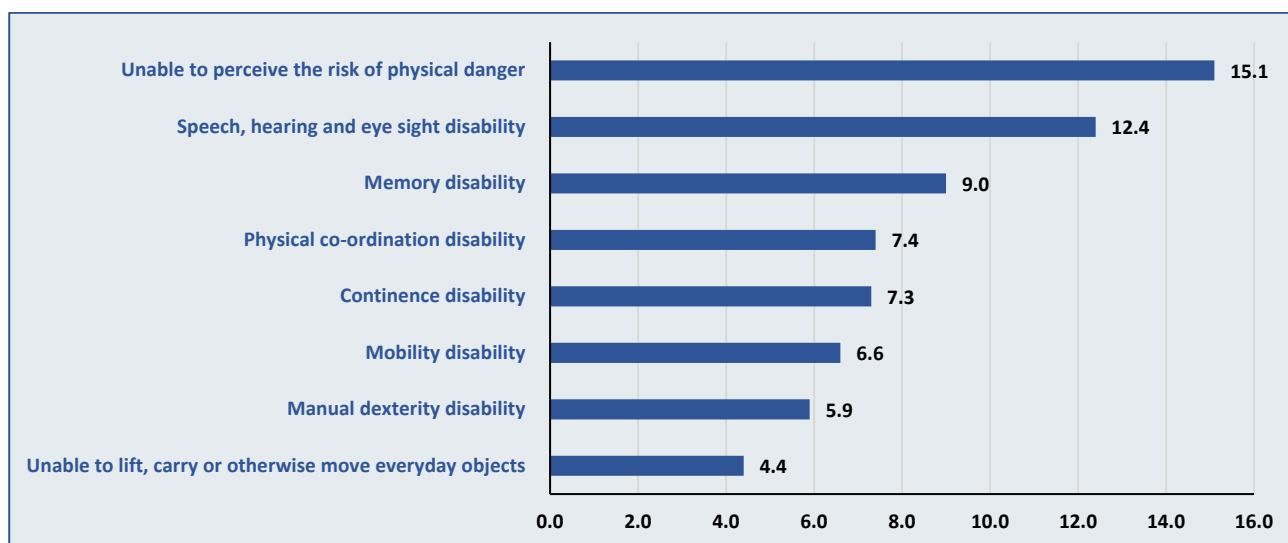
Wales

Wales’s 2021 Census findings record that 6.7% of children aged 0-15 were reported as disabled, with this breaking down as:

- 2.9% of 0-15 year olds were reported as having their day-to-day activities limited a lot by their disability.
- 3.8% of 0-15 year olds were reported as having their day-to-day activities limited a little by their disability.

The [Children Receiving Care and Support Census](#) is a dataset that comes from a statutory return that has to be submitted annually to the Welsh Government by each Welsh local authority about all the children in receiving care and support. The data for Wales finds that of the 17,190 children in need on 31 March 2022, 21.5% had a recorded disability. Like England, a breakdown by type of disability is provided – although different categories are used to those in England. Unable to perceive the risk of physical danger and speech, hearing and eyesight disability were the most widely recorded concerns.

Figure 8: Disabilities of children receiving care and support by disability, 2022, Wales (% of all children receiving care and support)



Source: Children Receiving Care and Support Census 2022

Note: Multiple forms of disability can be recorded

The data for Wales also provides a breakdown of disabled children according to the different types of care and protection they were receiving.

- 4.7% of children on the Child Protection Register, but who were not 'looked after', had a recorded disability.
- 10.0% of 'looked after' children had a recorded disability.
- 36.7% of children receiving care and support, but who were neither 'looked after' nor on the Child Protection Register, had a recorded disability.

The percentage of children in Wales who are on the Child Protection Register or are 'looked after' who are disabled is closely comparable to the percentages in Scotland.

Northern Ireland

Northern Ireland's [2021 Census](#) had a slightly broader question than in England and Wales as it asks about a health problem or disability. This recorded that 8.1% of children aged 0-15 were reported as having a long-term health problem or disability, with this breaking down as:

- 3.0% of 0-15 year olds were reported as having their day-to-day activities limited a lot by their health problem or disability.
- 5.1% of 0-15 year olds were reported as having their day-to-day activities limited a little by their health problem or disability.

The [Children's Social Care Statistics for Northern Ireland](#) are a statutory annual collection from each of Northern Ireland's five Health and Social Care Trusts about the number and characteristics of children in need, children on the Child Protection Register, children in care, children's homes, day care provision, foster carers and young people subject to the Care Leaving Act. The 2022/23 publication reported that 20.5% of the 22,875 children in need had a disability. The breakdown available by type of disability shows a similar pattern to England with learning disability and autism

and attention deficit hyperactivity disorder (ADHD) being the most widely recorded categories.

- 9.0% of children in need had a learning disability.
- 8.4% of children in need with autism and attention deficit hyperactivity disorder (ADHD).
- 2.2% of children in need had a physical disability.
- 0.6% of children in need had a sensory disability.
- 0.3% of children in need had an uncategorised 'other' disability.

Key summary points

- Disabled children are understood to be at an increased risk of harm and abuse compared to their non-disabled peers. This increased prevalence is reflected in the data for England, Wales and Northern Ireland where there are proportionately more 'children in need' recorded as disabled (13% in England, 22% in Wales, and 21% in Northern Ireland) than the proportion of disabled children recorded in their total children's population figures (6% in England, 7% in Wales, and 8% in Northern Ireland).
- The increased prevalence is less apparent within Scotland's data, as 5% of children on the Child Protection Register and 10% of 'looked after' children were assessed as having a disability. Addressing the high proportions of children in these collections who did not have their disability assessed, recorded or known would be an important action in enhancing Scotland's data.

6. Scotland local authority area data on disabled children

The national Scotland data ([Sections 4](#) and [5](#)) shows notable variations in how disability is captured across different service types. However, the level of variation is accentuated when the data, where available, is collated and analysed at the local authority area level.

Figure 9 presents the data for each of Scotland's 32 local authority areas for four indicators and this shows that across these areas there is substantial differentiation and variation:

- For the 27-30 month developmental concerns data, the data ranges from 10.2% to 27.7%.
- For the school pupil data assessed and/or declared as disabled, the data ranges from 0.8% to 14.5%.
- For school pupils with additional support needs, the data ranges from 17.3% to 48.7%.
- For 'looked after' children assessed as disabled, the data ranges from 0% to 28.9%.

The scale of this variation further confirms the lack of consistency across Scotland in how disability (and/or developmental concerns or additional support needs) is defined, understood, identified, assessed and/or recorded by practitioners.

Figure 9: Local Authority Data for Developmental Concerns, Disability and Additional Support Needs Indicators, 2022-23

	% of 27-30 months with a developmental concern	% of school pupils assessed and/or declared as having a disability	% of school pupils with Additional Support Needs	% of looked after children assessed as disabled
Aberdeen City	10.2	1.9	39.5	15.8
Aberdeenshire	10.7	2.0	48.7	14.4
Angus	17.4	1.7	32.1	13.0
Argyll & Bute	14.7	6.6	35.1	23.6
Clackmannanshire	17.5	1.6	33.5	4.9
Dumfries & Galloway	20.9	4.5	39.0	6.1
Dundee	18.2	7.7	36.3	16.2
East Ayrshire	19.2	2.3	27.3	3.8
East Dunbartonshire	17.2	1.8	24.6	14.1
East Lothian	13.1	5.1	36.2	22.1
East Renfrewshire	17.0	1.3	24.7	28.9
Edinburgh, City of	11.7	4.8	44.7	5.0
Eilean Siar	25.3	0.9	35.2	16.1
Falkirk	16.4	1.8	33.4	1.4
Fife	18.9	3.1	34.8	0.0
Glasgow	25.6	4.0	40.1	8.3

Highland	16.7	3.3	42.8	19.0
Inverclyde	24.9	5.0	35.0	8.1
Midlothian	14.0	2.7	38.1	6.9
Moray	12.7	5.4	41.7	17.1
North Ayrshire	20.5	4.1	36.8	18.8
North Lanarkshire	20.4	0.8	17.3	5.5
Orkney	12.9	1.9	41.6	0.0
Perth & Kinross	17.4	1.1	34.5	4.4
Renfrewshire	21.0	1.1	31.1	8.8
Scottish Borders	11.5	1.2	37.4	3.4
Shetland	19.9	2.4	40.4	21.1
South Ayrshire	15.0	14.5	35.8	12.7
South Lanarkshire	18.1	1.2	29.8	12.2
Stirling	17.6	2.8	35.5	9.1
West Dunbartonshire	27.7	5.1	42.8	10.6
West Lothian	19.4	1.4	36.7	9.4
Scotland	17.9	3.1	36.0	9.6

Source: Public Health Scotland Early child development statistics - Scotland 2022 to 2023; Scottish Government Pupil Census, 2022/23; Scottish Government Children's Social Work Statistics, 2022/23

To better understand the variations at the local level, for this review, exploratory conversations were held with seven local authority data officers who are responsible for the local reporting of children's social work data to the Scottish Government. Box 8 summarises the key points raised in these discussions, highlighting that the rationalisation of the disability-related question used in the Scottish Government's Children's Social Work Statistics return since 2015-16 has arguably increased the variation in recording.

Box 8: The recording of disability by local authorities

Local authority data officers recognised the variations in how disability is defined and recorded, which in turn leads to the variations in the disabled children's statistics.

It is apparent that some local authority social work systems have, and continue to use, legacy disability fields dating back to when the Scottish Government's Children's Social Work Statistics return required Additional Support Needs categories to be recorded. The change to the current disability question was made for the 2015-16 collection and has been used since. For information, the historic Additional Support Needs categories were:

- Autistic Spectrum disorder
- Combined sight and hearing loss (deafblind)
- Hearing impairment
- Language and communication disorder
- Learning disability

- Multiple disabilities
- Mental health problems
- Physical or motor impairment
- Social, emotional or behavioural difficulties
- Visual impairment
- Other chronic illness/disability
- Not yet assessed
- Unknown
- No disability

One local authority outlined how they will retain sub-categories but will modify the list of categories above in their move to a new IT system for recording. The proposed categories are:

- Asperger's Syndrome
- Behaviour
- Classical autism
- Communication
- Consciousness
- Disabled under the Disability Discrimination Act
- Hand Function
- Hearing
- Incontinence
- Learning
- Mobility
- Other Autism Spectrum Diagnosis
- Personal Care
- Vision

Another local authority explained that it records whether a child is affected by another person's disability (for example, a parent, carer, brother or sister) to provide some insight into children who are young carers.

Where the Additional Support Needs fields exist on social work IT systems, data officers use these Additional Support Needs fields to determine whether a child has a disability for the current reporting for the Children's Social Work Statistics.

Some shared reflections on the recording of disability were:

- The different categories do not have supporting definitions that might boost consistency in recording.
- The disability fields are not mandatory for social workers to complete.
- A formal diagnosis of a disability is widely needed for the disability (or sub-category) to be recorded. The implications of this are:
 - It can take time to get a medical/health assessment and diagnosis, so this can contribute to the high proportion of children's disability status being recorded as 'not yet assessed' or 'not known' – particularly in child protection where children may only recently have become identified for support.
 - The need for a diagnosis reinforces a medical model of disability.

- Where there are children whose disability status is recorded as 'not yet assessed' or 'not known', some data officers do seek to address these as part of data validation but often this requires a manual exercise. It is not, for example, possible to link children's data across social work, health and education IT systems.

There is strong interest in enhancing the recording and collection of disabled children's statistics. Suggested ways forward were:

- Agreeing a national set of disability sub-categories that could be embedded within social work IT systems. The number of sub-categories should be kept manageable (for example, no more than 10-12 sub-categories) as this enables the sub-categories to be quite wide and inclusive. It was felt that a large number of detailed sub-categories would imply the need for specific, medical knowledge and consequently social workers may be less confident to assess this.
- Developing clear definitions for each disability sub-category so that social workers are more confident in their recording of disability.
- Creating associated fields relating to presence of a diagnosis. There could therefore be a field to record disability based on the social worker's judgement (irrespective of a diagnosis) and another field if a medical assessment/ diagnosis has been completed or received.
- Having an open qualitative field for social workers to record any additional information relating to the child's disability.
- Ensuring social workers can change a child's disability record as their disability changes over time.

There was also interest in whether social work data could be linked to the (education) SEEMIS system to help validate disability data.

Key summary points

- At the local authority area level, Scotland's data on disabled children and/or children with additional support needs shows greater variations than those identified across different national statistical collections. For example, local authority reporting varied from:
 - 1% to 15% of school pupils assessed and/or declared as disabled
 - 0% to 29% of 'looked after' children assessed as disabled.
- The variations are a consequence of many factors, including: different definitions and that these lack supporting explanatory descriptors; disability fields not being mandatory; and relying (and waiting) on medical diagnoses.
- Data collectors acknowledge the variations in how disabled children are identified and recorded across different statistical collections, and are keen to address this.

7. Mapping Scotland's disability definitions

The Scottish Government (2022) *Data collection and publication guidance: Disability* builds on the UK's Equality Act 2010 definition of disability to offer a harmonised suite of disability questions for use in surveys in Scotland. However, while there is widespread adherence to The Equality Act 2010 definition, this review found that the full set of disability questions contained in the Scottish Government (2022) guidance is not being consistently used across Scotland's children's statistical collections.

In reviewing the different ways that disability and/or additional support needs are asked about and defined in Scotland's children's statistical collections, the main areas of variation are:

- Some collections (Early Learning and Childcare, School Pupil Census, and Children's Social Work) record disability and additional support needs separately, while others (Census, colleges, universities and apprenticeships) ask about disability and additional support needs within a combined set of questions. The Scottish Government (2022) guidance proposes that a combined set of questions is used.
- Where disability is specifically asked about, the collections use a binary (yes/no) question only and do not ask a follow-up question about the type or impact of the disability on day-to-day activities. Information about the type of disability is instead captured in the additional support needs questions.
- The number of disability and/or additional support needs categories asked about ranges from eight to twenty-two.
- The Universal Health Visiting Pathway does not ask about disability and additional support needs, and instead asks about developmental concerns.

The need for greater consistency in how disability and additional support needs are captured across Scotland's children's statistics is clear. To help understand the level of change needed, plotted against the nine Scottish Government (2022) categories, Figure 10 maps how disabled children and children with additional support needs¹ are currently defined within Scotland's different national statistical recording and reporting. Figure 10 shows:

- Data is being collected by some or all of the collections for eight of the nine Scottish Government (2022) categories. No data is being collected in relation to 'Memory'.
- Data for the Scottish Government (2022) 'Learning/Understanding/ Concentrating' and 'Social or behavioural' categories is being recorded by some collections but at a more disaggregated level. For example, separating out learning disability and learning difficulty as separate categories within 'Learning/ Understanding/Concentrating'.
- Data for the Scottish Government (2022) 'Mobility' and 'Dexterity' categories is mainly being captured within a combined physical disability category.

¹ In mapping the Additional Support Needs, 'non-disability' categories such as English as an Additional Language or 'Looked after' / care experienced have not been included

- The Scottish Government (2022) guidance does not include data relating to speech, language and communication, yet data relating to this difficulty is widely captured across the different collections.

Figure 10: Mapping of Disability Categories contained across Children’s Statistical Collections in Scotland

Scotland statistical collections (excluding Children’s Social Work Statistics as contains no disability or additional support needs breakdown)							International
Scottish Government’s Data collection and publication guidance: Disability	Scotland 2022 Census	Health Visitor Pathway Assessment	Early Learning and Childcare Additional Support Needs	Schools Additional Support Needs	College and University Declared Disability	Skills Development Scotland Modern Apprenticeship	Washington Group/UNICEF Module on Child Functioning
Vision	Blindness or partial sight loss	Vision	Visual or hearing impairment, or deafblind	Visual impairment	Blind / serious visual impairment uncorrected by glasses	Blind / visual impairment uncorrected by glasses	Seeing
Hearing	Deafness or partial hearing loss	Hearing		Hearing impairment	Deaf / serious hearing impairment	Deaf / hearing impairment	Hearing
Mobility	Physical disability	Gross motor	Physical or motor impairment	Physical or motor impairment	Physical impairment or mobility issues	Physical impairment or mobility issues	Mobility
Dexterity		Fine motor					Fine Motor
Learning/ understanding/ concentrating	Learning disability	Problem solving	Learning difficulties and dyslexia	Learning disability		Learning disability	Learning
	Learning difficulty			Dyslexia			Attention and concentrating
				Other specific learning difficulty	Specific learning difficulty	Specific learning difficulty	
Mental health	Mental health condition		Physical or mental health	Mental health	Mental health condition	Mental health difficulty	Anxiety Depression
Social or behavioural (e.g. ASD, ADHD)	Developmental disorder	Personal / social	Social, emotional and behavioural	Social, emotional and behavioural			Controlling Behaviour
		Emotional / behavioural	Autism spectrum disorder	Autism spectrum disorder			
				Communication support needs			
Memory							Remembering
Stamina/breathing /fatigue	Long-term illness, disease or condition			Physical health problem	Long standing illness or health condition	Long standing illness or health condition	
	Full or partial loss of voice or difficulty speaking	Speech, language and communication	Language, speech and communication	Language or speech	Social / communication impairment	Social / communication impairment	Communication/ Comprehension
							Self-care
							Playing
							Relationships

* ‘Speech, hearing and eyesight’ is included in two places within *Figure 11* as the indicator covers ‘seeing’, ‘hearing’ and ‘communication/comprehension’

The mapping suggests that the Scottish Government (2022) guidance can provide the means through which greater consistency could be achieved, provided some further development work is undertaken to ensure all forms of disability are included, for example, including a question that captures speech, language and communication difficulties, and that the questions and examples are refined so that these encompass the day-to-day activities of children.

An alternative to following the Scottish Government (2022) guidance as the model would be to consider the functional difficulty domains used in the Washington Group/UNICEF Module on Child Functioning. In Figure 10, Scotland's current recording is also plotted against these 14 domains and similar conclusions can be reached from the mapping against the Scottish Government (2022) guidance categories. For example:

- Data is being collected by some or all of the collections for 10 of the 14 functional difficulties. No data is being collected in relation to 'Remembering', 'Self-care', 'Playing' and 'Relationships' domains.
- The functional difficulties do not include long-term illness or health conditions, yet data relating to illness or poor health is widely captured across the different collections.

Key summary points

- There is significant variation in how disability and additional support needs are collected across Scotland's children's statistics.
- The Scottish Government (2022) guidance and the Washington Group/UNICEF Module on Child Functioning both offer mechanisms for more consistent collection. Importantly, both propose that disability and additional support needs are asked as a single set of questions rather than having separate disability and additional support needs questions.
- Of the two approaches, the Scottish Government (2022) guidance appears to be most closely aligned to Scotland's existing collections and, with some further development, would bring the consistency sought.
- Given the similarities between the Scottish Government (2022) and the Washington Group/UNICEF Module on Child Functioning domains, there would also be the opportunity for Scotland to provide data for international comparative analysis if the Scottish Government (2022) guidance was more widely adopted.

8. Conclusions and next steps

The collection of good quality information about disabled children is critical to increasing the awareness and visibility of disabled children and their needs and experiences among policy makers, funders, leaders and managers, and ensuring that their support needs are better understood and met with the right support and investment. This review has sought to understand how disabled children, and particularly disabled children in need of care and protection, are defined and recorded in Scotland's statistical collections. The findings from the review confirm that collecting data on disabled children is not an easy task, with many factors affecting how disability is assessed and recorded, including there being multiple ways in which disability and additional support needs are defined and collected across Scotland's statistical returns.

The Scottish Government (2022) *Data collection and publication guidance: Disability* offers a constructive approach for the more consistent and enhanced collection of disabled children's statistics. The questions contained in the guidance ask about disability and additional support needs in a single set of questions, ask about different disabilities, and ask about the severity of the impact of the disabilities. These are all features that are consistent with the Equality Act 2010 and the Washington Group/UNICEF Module on Child Functioning. However, this review has found that the set of disability questions proposed by the guidance is not being used across Scotland's children's statistical collections, while there is also a need for further development work so that the guidance is more centred on the day-to-day experiences of children and child development.

The number of statistical returns involved – spanning census, health, early learning and childcare, education, social work, college, university and apprenticeship statistical collections – means change will take time. The steps outlined here are therefore designed to introduce the Scottish Government (2022) *Data collection and publication guidance: Disability* in a phased and purposeful way that will in time bring consistency across Scotland's different children's statistical collections and provide a more robust and complete picture of the needs of all our children.

Suggested next steps

1. Refresh the Scottish Government (2022) *Data collection and publication guidance: Disability* so that it reflects children's lives

The Scottish Government (2022) *Data collection and publication guidance: Disability* can support the more consistent and enhanced collection of disabled children's statistics, but further development work is advised so that the guidance is better able to reflect the circumstances in which children develop and live their lives. In particular, there ought to be consideration of:

- Including speech, language and communication difficulties within the set of questions;
- Providing illustrative examples to support more accurate recording of disabled children. For example, remembering to pay bills and gardening are examples currently given which speak to adult experiences and tasks;

- Clarifying who can assess, declare and record disability, with the recommendation that this is via agreement between the practitioner (e.g. health visitor, social worker or teacher), parent/carer(s) and/or child; and
- Referring to '(functional) difficulties' in the guidance rather than 'disabilities', 'illnesses', 'conditions' or 'impairments', as this more inclusive '(functional) difficulty' approach to recording may mean that a formal medical diagnosis or assessment is not required before disability can be recorded, and identifies a need more readily.

The work to further develop the Scottish Government (2022) guidance or questions should be done in collaboration with stakeholders who represent different perspectives and interests in relation to disabled children. For example, stakeholders with expertise in relation to different disabilities and additional support needs, legislative requirements, policy, practice, and data. The aim should be to develop guidance and questions that can be collected with confidence at the child and practitioner level and provide meaningful data to relevant stakeholders.

2. Test the refreshed guidance in one children's statistical collection

Once the Scottish Government (2022) *Data collection and publication guidance: Disability* is refreshed and set of questions agreed, these should be tested in one of Scotland's children's statistical collections. It is proposed that this be done in Scotland's Children's Social Work Statistics collection because of the high proportion of children who did not have their disability assessed, recorded or known. The testing should be done in partnership with a small number of local authorities in the first instance. During the testing period, there should be regular monitoring of the data collected and feedback sought from social workers and data officers on how the collection has been working locally.

3. Re-run analysis of Scottish Government statistical collections using refreshed guidance

Another aspect of the testing should be to ask other Scottish Government statistical collections (e.g. early learning and childcare and schools/education) to re-run their analysis of their most recent year's children's data using the refreshed guidance. This exercise would provide a different analysis of the number and characteristics of disabled children in Scotland and offer greater understanding of the extent to which alterations to Scotland's statistical collections are required.

4. Undertake data linkage exercise across different children's statistical collections

As a separate exercise, there is the potential to link the data for individual children that is contained in health visitor, early learning and childcare, school education, and children's social work statistical returns and analyse whether and how individual children are recorded as disabled in each of these returns. The findings from the data linkage exercise could provide further evidence of the variations in how disabled children are

recorded across the systems used by multi-agency partners and consequently challenge partners to improve their levels of data sharing to ensure children's support needs are captured and being met.

References

- Brady, G and Franklin, A (2023) 'I am more than just my label': Rights, fights, validation and negotiation. Exploring theoretical debates on childhood disability with disabled young people, *Sociology of Health and Illness*, 45:1376–1392.
- Cappa, C, Petrowski, N and Njelesaniet, J (2015) Navigating the landscape of child disability measurement: A review of available data collection instruments. *ALTER, European Journal of Disability Research*, 9, 317-330.
- Colver, A (2005) A shared framework and language for childhood disability. *Developmental Medicine & Child Neurology*, 47:780–784.
- Crialesi, R, De Palma, E and Battisti, A (2016) Chapter 10. Building a "Module on Child Functioning and Disability" in Altman, B eds (2016) *International Measurement of Disability: Purpose, Method and Application - The Work of the Washington Group*.
- Franklin, A, Brady, G and Bradley, L (2020) The medicalisation of disabled children and young people in child sexual abuse: Impacts on prevention, identification, response and recovery in the United Kingdom, *Global Studies of Childhood*, 10(1) 64–77.
- Franklin, A, Toft, A, Herson, J, Greenaway-Clarke, J and Goff, S (2022) *UK Social Work Practice in Safeguarding Disabled Children and Young People*. What Works for Children's Social Care.
- Jones, L, Bellis, M, Wood, S, Hughes, K, McCoy, E, Eckley, L, Bates, G, Mikton, C, Shakespeare, T and Officer, A (2012) Prevalence and risk of violence against children with disabilities: a systematic review and meta-analysis of observational studies, *The Lancet*, 380 (9845) 899-907.
- Legano, L, Desch, L, Messner, S, Idzerda, S and Flaherty, E (2021) Maltreatment of Children With Disabilities. *Pediatrics*, 147(5).
- Loeb, M, Mont, D, Cappa, C, De Palma, E, Madans, J and Crialesi, R (2018) The development and testing of a module on child functioning for identifying children with disabilities on surveys. I: Background, *Disability and Health Journal*, 11: 495-501.
- Meltzer, H (2016) Chapter 9: The Challenges of Conducting National Surveys of Disability Among Children in Altman, B eds (2016) *International Measurement of Disability: Purpose, Method and Application - The Work of the Washington Group*.
- Scottish Government (2022) *Data collection and publication guidance: Disability*. <https://www.gov.scot/publications/data-collection-publication-guidance-disability/>
- Stalker, K and McArthur, K (2012) Child Abuse, Child Protection and Disabled Children: A review of recent research, *Child Abuse Review*, 21: 24–40.
- Sullivan, P and Knutson, J (2000) Maltreatment and disabilities: A population-based epidemiological study. *Child Abuse & Neglect*, 24(10), 1257–1273.
- UN Commission on Human Rights, *Convention on the Rights of the Child*, 7 March 1990, E/CN.4/RES/1990/74, available at: <https://www.refworld.org/docid/3b00f03d30.html>

UN Committee on the Rights of the Child (CRC), *General comment no. 5 (2003): General measures of implementation of the Convention on the Rights of the Child*, 27 November 2003, CRC/GC/2003/5, available at: <https://www.refworld.org/docid/4538834f11.html>

UN Committee on the Rights of the Child (CRC), *General comment No. 9 (2006): The rights of children with disabilities*, 27 February 2007, CRC/C/GC/9, available at: <https://www.refworld.org/docid/461b93f72.html>

UN General Assembly, *Convention on the Rights of Persons with Disabilities*, 13 December 2006, A/RES/61/106, Annex I, available at: <https://www.refworld.org/docid/4680cd212.html>

UN Committee on the Rights of Persons with Disabilities (CRPD), *General comment No. 6 (2018) on equality and non-discrimination*, 26 April 2018, CRPD/C/GC/6, <https://www.ohchr.org/en/documents/general-comments-and-recommendations/general-comment-no6-equality-and-non-discrimination>

UNICEF (2021) *Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities*. <https://data.unicef.org/resources/children-with-disabilities-report-2021/>



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