

Increasing the visibility of disabled children in Scotland's children's statistics

Findings from a test collection



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Introduction

The collection of good quality statistics is critical to increasing the awareness and visibility of disabled children and to better understanding their needs. Good quality statistics are particularly important within children's care and protection services because research shows that disabled children¹ are three to four times² more likely to experience harm and abuse than their non-disabled peers.

In May 2024, analysis published in CELCIS's paper '[Are disabled children visible in Scotland's children's statistics?](#)' found that differences in how disability is defined across statistical collections, as well as practitioners not feeling fully confident when completing disability data questions, are leading to inconsistencies in the data collected. This makes it difficult to know the number of disabled children living in Scotland and understand their needs.

One year on, the same conclusion can be reached when reviewing data published in the past 12 months: inconsistencies remain. Figure 1 shows continued variations across different datasets: from 1.9% of children in early learning and childcare centres recorded as disabled, to 17.0% of young people starting a Modern Apprenticeship self-reporting as disabled.

¹ Throughout this paper, the term 'disabled children' is used because, consistent with the social model of disability, 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).

² 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.

Sullivan, P and Knutson, J (2000) Maltreatment and disabilities: A population-based epidemiological study. *Child Abuse & Neglect*, 24(10), 1257-1273.

Figure 1: Selected disability data published in 2024-2025



Aims of the project

In response to the inconsistencies of the disability data collected in Scotland, we (CELCIS) wanted to see whether an improved approach to identifying and recording disability was possible. To do this, we knew we had to work with other organisations with experience of supporting disabled children or collecting children's data because disability is a complex and sensitive area of practice, meaning different insights are needed to develop a robust set of disability indicators.

Identifying a test 'site'

The first task was to identify a statistical collection where a set of disability indicators could be developed and tested. This needed to be a

standalone collection where the test data would not impact on the time series data of official, published statistics.

The Joint Investigative Interview data collection met this criterion. Joint Investigative Interviews are a key part of Scotland's child protection process and, while data is collected and reported locally, this data is not reported in the Scottish Government's national Children's Social Work Statistics.

There were also other reasons why the Joint Investigative Interview data collection was a conducive dataset to develop and test a new approach:

- Joint Investigative Interviews involve multi-agency partners, specifically social work and police, so this would provide different practice insights;
- The new approach to joint investigative interviewing (the 'Scottish Child Interview Model') incorporates improved planning tools and strategies that ensure a bespoke interview plan is created for every child. Key within these improved planning tools and strategies is the Plan for the Child's Needs which (along with a range of other relevant information) includes detail of physical and mental health illnesses or conditions impacting on the child so that these can be taken into account in supporting the child's participation in the interview;
- Several Joint Investigative Interviewing partnerships were keen to participate in this project, with the shared ambition of improving the disability data they collect; and
- There was an additional layer of support to local partnerships built in through the existing role of the National Joint Investigative Interviewing Project Team.

Project partners

Led by CELCIS, seven local Joint Investigative Interview Partnerships (Ayrshire, Dumfries and Galloway, Glasgow, Highland, Lanarkshire, North Strathclyde, and Western Isles) and the National Joint Investigative Interviewing Project Team (which comprises of COSLA, Social Work Scotland and Police Scotland) agreed to participate in the project. The Scottish Government, The Alliance and the Fraser of Allander Institute also provided 'critical friend' support by commenting on draft versions of the test disability indicators and making connections to wider research and data developments.

Project timeline

There were three key phases of the project:

- In May and June 2024, two workshops were held with project partners to discuss and agree on a set of disability indicators for testing.
- From August 2024 to July 2025, the data for the test disability indicators were collected by the seven Joint Investigative Interview Partnerships. Anonymised, aggregate data was then shared with CELCIS on a quarterly basis for analysis, while regular check-ins were held with the local partnerships to understand how the collection was working.
- In June and July 2025, project partners came back together to reflect on the year's data collection and discuss and agree on revisions for the 2025-2026 collection year.

Developing the test indicators

In developing the indicators, the project partners agreed on some key principles that the indicators would adhere to. The indicators would:

- Align with the UN Convention on the Rights of Persons with Disabilities, the UK's Equality Act 2010, the social model of disability³(which encourages us to ask in an inclusive and non-stigmatising manner what people have difficulty doing), and other UK and Scotland disability data collections.
- Enable different disabilities and conditions to be recorded, with each condition having child-relevant definitions to support consistency of understanding and recording.
- Be worded to support uptake and use within other statistical collections.

Project partners also highlighted two key factors that needed to be acknowledged within the indicators and are grounded in the reality of children's experiences:

- Children's presenting health condition(s) or illness(es) can be related to their experience of trauma. The disability data collected must therefore be interpreted with a trauma lens.

³ 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.

- Children often face long waiting times for medical assessments and diagnoses.

The test indicators

Figure 2 sets out the test indicators that were developed by the project partners. In supporting their use by the Joint Investigative Interviewers, the following guidance and information was also provided:

- As the Equality Act 2010 definition of disability underpinned the collection, a child should be recorded as disabled if they have any physical or mental health condition or illness that has a substantial, long-term adverse effect on their ability to do any normal day-to-day activities.
- Multiple conditions can be recorded for each child, and should be recorded where appropriate.
- Each condition has been worded using inclusive, non-stigmatising language, with child-relevant exemplar descriptions provided.
- A 'present but without medical diagnosis' option is provided in recognition of the long waiting lists for medical assessments and diagnoses.
- The recording of the indicators should be completed after the Joint Investigative Interview has taken place. This is designed to enable an informed understanding of each child's conditions to be built because it follows information sharing across multi-agency partners, planning for the interview, and direct interaction with the child concerned.

Figure 2: Test disability indicators, 2024-2025

Disability: Based on the information shared (including case files, medical records and views shared by the child, parents and/or carers) and/or practitioners' experience of engaging with the child			
Q1: Does the child have any physical or mental health condition(s) or illness(es) that has a substantial, long-term adverse effect on the child's ability to do any normal day-to-day activities? Please select all conditions or illnesses that the child has, distinguishing between whether the conditions or illnesses are 'medically diagnosed' or 'present but without medical diagnosis*'			
* 'Yes – present but without medical diagnosis' = the information shared with practitioners and/or practitioners' experience of engaging with the child and their parent(s) or carer(s) indicates that the child has a physical or mental health condition or illness, but a medical diagnosis has not been made and/or an assessment is pending.			
	Yes – medically diagnosed	Yes – present but without medical diagnosis*	No
Vision (e.g. blindness or partial sight)			
Hearing (e.g. deafness or partial hearing)			
Mobility (e.g. difficulties walking or climbing stairs)			
Dexterity (e.g. difficulties using their hands, lifting or carrying)			
Learning and understanding: Learning disability (e.g. Down's syndrome, acquired brain injury, neonatal brain damage, or cognitive impairment; must be medically diagnosed)		N/A – medically diagnosed only	
Learning and processing information: Learning difficulty (e.g. dyslexia, dyscalculia or dyspraxia)			
Social interaction (e.g. related to autism, Asperger's Syndrome or ADHD)			
Mental health (e.g. self-harm, suicide ideation, anxiety, bipolar disorder, eating disorder, depression, panic attacks or schizophrenia)			

Speech, language and communication (e.g. full or partial loss of voice or difficulties verbalising their thoughts or making themselves understood, excluding English as a Secondary Language)			
Long-term illness or health condition (e.g. a life-limiting illness, stamina, breathing, or fatigue difficulties)			
Other			
Q2: Please record any further information about the child's physical or mental health condition(s) or illness(es) (for example, any specific conditions that affect their ability to do normal day-to-day activities, or different views of the child's disability)			

The results: overall prevalence of disability

Across the seven Joint Investigative Interview partnerships and the four quarters for which they used the test indicators, data for 1,075 children interviewed in a Joint Investigative Interview was collected and then shared with CELCIS.

Using the test indicators, 42.7% of the children interviewed in a Joint Investigative Interview in 2024-2025 were recorded as having one or more of the conditions set out in the test collection.

For comparison, baseline data from the seven Joint Investigative Interview partnerships using the existing question 'Disability: yes; no; chose not to disclose; unknown' found that 6.6% of the children interviewed in a Joint Investigative Interview in 2023-2024 were recorded as disabled.

Figure 3: Prevalence of disability; baseline and test collection

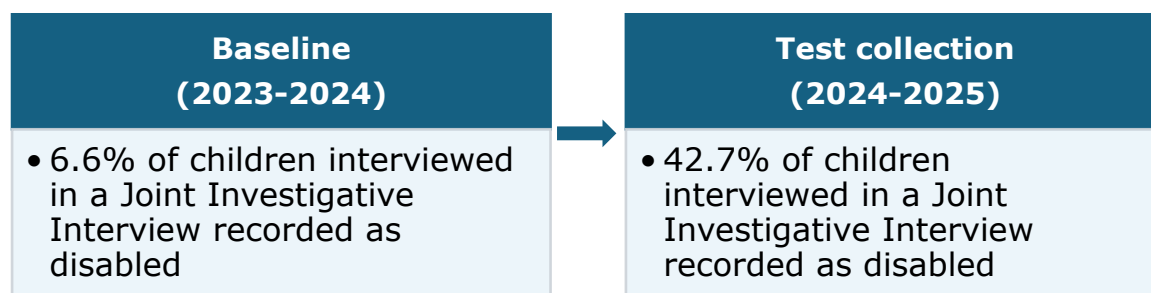


Table 1 shows similar recording levels across the seven Joint Investigative Interview partnerships, but with some local variance.

Table 1: Disability prevalence in each Joint Investigative Interview partnership area

Ayrshire	43.5%	Lanarkshire	30.5%
Dumfries & Galloway	38.8%	North Strathclyde	49.7%
Glasgow	58.9%	Western Isles	45.0%
Highland	45.0%	All	42.7%

The results: by condition

The test indicators enabled recording of the multiple conditions that a child has. The 2024-2025 data showed that 18.4% of the children interviewed in a Joint Investigative Interview had two or more conditions recorded, meaning almost half of the children recorded with a disability had two or more conditions.

Table 2 shows the conditions recorded, including whether the conditions were medically diagnosed or not. The most commonly recorded conditions were:

- A social interaction condition (e.g. related to autism, Asperger’s Syndrome or ADHD): 26.5% of the children interviewed in a Joint Investigative Interview.
- A mental health condition: 18.0% of the children interviewed in a Joint Investigative Interview.
- A learning difficulty: 9.3% of the children interviewed in a Joint Investigative Interview.

Table 2 also shows the importance of having the ‘present but without medical diagnosis’ option. Without this, only a partial picture of children’s conditions would be provided.

Table 2: Conditions of children interviewed in Joint Investigative Interviews – test collection, 2024-25

	Yes – medically diagnosed	Yes – present but without medical diagnosis	Total
Vision	1.2%	0.7%	2.0%
Hearing	0.6%	0.0%	0.6%

Mobility	0.7%	0.2%	0.9%
Dexterity	0.2%	0.2%	0.4%
Learning disability	2.1%	N/A*	2.1%
Learning difficulty	3.4%	5.9%	9.3%
Social interaction	10.9%	15.6%	26.5%
Mental health	4.8%	13.2%	18.0%
Speech, language and communication	0.8%	4.4%	5.2%
Long-term illness or health condition	2.8%	0.6%	3.3%
Other	2.0%	0.8%	2.8%

From the data of 1,075 children

** learning disability must be medically diagnosed*

Feedback from local partners

The increase in the recording of disability from 6.6% in 2023-2024 to 42.7% in 2024-2025 raised the prospect that the test indicators had led to an over-recording of children's conditions. This was discussed in the regular check-ins with the local partnerships and the unanimous feedback was that the data generated by the test indicators did accurately reflect the needs and conditions of the children they are engaging with in Joint Investigative Interviews.

The regular check-ins also found that the test indicators had had wider beneficial impacts on practice. Local partners shared that the test indicators had led to:

- Better identification of children's developmental and complex needs, so this had helped practitioners to plan each interview to best meet child's needs.
- Improved engagement of children in the Joint Investigative Interviews because the planning is much more considered and individualised.
- Sharper focus on children's disability within other parts of the child protection process, such as at the Inter-agency Referral Discussion (IRD) stage where information about children is shared by multi-agency partners.

- Greater understanding of the learning and development support that interviewers need in order to better understand and respond to disabled children.

Revising the indicators

Responding to interest from Public Health Scotland in including the indicators within the Universal Health Visitor Pathway Assessments, CELCIS took the opportunity to work with Public Health Scotland to further refine the indicators. The revised indicators are presented in Figure 4, with the revisions primarily focused on expanding the definitions for each condition to further improve consistency of recording across different practitioners.

Figure 4: Revised disability indicators, 2025-2026

Based on the information shared (including case files, medical records and views shared by the child, parents and/or carers) and/or practitioners' experience of engaging with the child			
<p>Q1: Does the child have any physical or mental health condition(s) or illness(es) that has a substantial, long-term adverse effect on the child's ability to do any normal day-to-day activities?</p> <p>Please select all conditions or illnesses that the child has, distinguishing between whether the conditions or illnesses are 'medically diagnosed' or 'present but no current diagnosis and/or assessment pending*'</p> <p>* 'Yes – present but no current diagnosis and/or assessment pending' = the information shared with practitioners and/or practitioners' experience of engaging with the child and their parent(s) or carer(s) indicates that the child has a physical or mental health condition or illness, but a medical diagnosis has not been made and/or an assessment is pending.</p>			
	Yes – medically diagnosed	Yes – present but no current diagnosis and/or assessment pending *	No
<p>Vision</p> <p>Difficulty with seeing - e.g. blindness, partial sight, blurred vision or visual field loss</p> <p>Not applicable if sight fully corrected when wearing glasses</p>			

<p>Hearing</p> <p>Moderate to severe hearing difficulties - e.g. deafness or partial hearing</p>			
<p>Mobility</p> <p>Difficulties crawling, walking or climbing stairs (as appropriate to age) without the use of aids, adaptations or support from another person</p>			
<p>Dexterity</p> <p>Difficulties using hands, lifting and/or carrying things (as appropriate to age) - e.g. fine motor skills/tasks of grasping, manipulating or releasing</p>			
<p>Learning and understanding: Learning disability</p> <p>Significant lifelong condition where more support is needed than their peers to understand new and/or complex information, learn new skills and to have a level of independence (as appropriate to age). This may be due to, for example, a genetic condition or brain injury during or after birth, or the reason may not be known</p> <p>Must be medically diagnosed</p>		<p>N/A – medically diagnosed only</p>	
<p>Learning and processing information: Learning difficulty</p> <p>Specific learning difficulties that impact the learning or processing of information - e.g. dyslexia, dyscalculia, dysgraphia or dyspraxia</p>			
<p>Social interaction and communication</p> <p>A difference that substantially impacts ability to communicate or interact socially with others (as appropriate to age) - e.g. autism or ADHD</p>			
<p>Mental health</p> <p>Mental ill health that impacts on day-to-day activities e.g. anxiety, depression, eating disorder, self-harm or suicide ideation. This</p>			

may present as persistent issues with sleep, concentration, and behaviour.			
Speech and language Difficulties understanding or producing speech and spoken language (as appropriate to age) – e.g. full or partial loss of voice, speech dysfluency or difficulties acquiring, understanding and producing language including verbalising their thoughts or feelings English as a Secondary Language should not be included			
Long-term illness or health condition Illnesses that impact stamina, breathing, fatigue, or a life-limiting illness or condition			
Other			
Q2: Please record any further information about the child’s physical or mental health condition(s) or illness(es) (for example, any specific conditions that affect their ability to do normal day-to-day activities, or different views of the child’s disability)			

Widening the use of the indicators

The revised indicators are now being used by all Joint Investigative Interview partnerships in Scotland and have been introduced into the Universal Health Visitor Pathway Assessments collection from October 2025. In November 2025, the indicators have been shared with Scotland’s Child Protection Committees to enable them to plan to use these in the Minimum Dataset for Child Protection Committees for the 2026-2027 reporting year.

Interest in the indicators from other stakeholders will be explored with the aim of widening their use across more of Scotland’s children’s statistical collections.

Further information

If you are interested in the indicators or would like any further information on their development and use, please get in touch at celcis@strath.ac.uk.