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Research Report

Trends in disability prevalence among young people: Insights from the Growing Up in Ireland study

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TRENDS IN DISABILITY PREVALENCE AMONG YOUNG PEOPLE: INSIGHTS FROM THE *GROWING UP IN IRELAND* STUDY

EMER SMYTH AND HELEN RUSSELL



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ABBREVIATIONS

ADHD	Attention deficit hyperactivity disorder
AME	Average marginal effect
ASD	Autism spectrum disorder
CES-D	Center for Epidemiological Studies-Depression
DCEDIY	Department of Children, Equality, Disability, Integration and Youth
ESPSEN	Education for Persons with Special Educational Needs Act
GUI	<i>Growing Up in Ireland</i> study
HRB	Health Research Board
ICD	International Classification of Diseases
LLC	Long-lasting illness, condition or disability
NCSE	National Council for Special Education
NIDD	National Intellectual Disability Database
OLS	Ordinary least square (regression model)
PISA	Programme for International Student Assessment
SDQ	Strengths and Difficulties Questionnaire
SEN	Special educational needs

EXECUTIVE SUMMARY

BACKGROUND TO THE STUDY

This report draws on analyses of the two cohorts of the *Growing Up in Ireland* (GUI) study to examine trends in the prevalence of disability among 13-year-olds over the decade 2011/2012 to 2021/2022. The report looks at changes over time in the size and composition of those with a long-lasting condition (LLC) or disability, at the presence of socio-emotional difficulties and/or depressive symptoms among these groups, and at a range of adolescent outcomes.

THE PREVALENCE OF LONG-LASTING CONDITIONS AND DISABILITY

The prevalence of disability is highly dependent on the definitions and measures used. As a result, changes in the measures used in GUI between cohorts, and between survey waves within cohorts, make it challenging to provide comparable estimates of the level and nature of disability over time. Nonetheless, GUI data offer the most comprehensive information on the experience of disability among young people in Ireland.

In this report, a distinction is drawn between young people with a long-lasting condition or illness who are not hampered by that condition (termed 'non-hampered LLC') and the group of young people who are hampered, at least to some extent, by that condition, for whom we use the term disability. Based on mother reports, the proportion of 13-year-olds with any LLC has increased from 24 per cent for Cohort '98 to 36 per cent for Cohort '08. The proportion of the total cohort who had received at least one *diagnosis* of a condition or disability grew from 16 per cent for Cohort '98 to 31 per cent for Cohort '08. The group with a disability (i.e. those who are hampered by a condition) increased from 6 per cent for Cohort '98 to 23 per cent for Cohort '08. This estimate is higher than figures from Census 2022, which used a different definition and where 14 per cent of 13-year-olds were reported to have a disability. The GUI data show a growth in the prevalence of disability and LLCs among all social groups over the period, though a shift in the gender composition is evident, with girls now as likely as boys to have an LLC or disability.

Changes in the classification of types of conditions, and small numbers in several groups, make it difficult to identify which particular conditions are driving the overall increase. Among those with an LLC, there is an increase in both respiratory and behavioural difficulties, the largest groups, over time. The increase is particularly marked for behavioural difficulties, growing from 1 to 17 per cent between cohorts at age 13. Respiratory problems increased but to a much lower level – from 3 to 5 per cent. Focusing on those with a disability only (that is, those who are hampered by that condition), the proportion with an

emotional/behavioural difficulty has increased from 1.1 per cent of the total cohort in Cohort '98 to 13.5 per cent in Cohort '08.

DISABILITY, HEALTH AND WELLBEING

Mothers were asked about the general health of their children, distinguishing between those who were very healthy and those who had at least some health problems. In both cohorts, health problems are more prevalent among those with an LLC or disability. Health problems are particularly prevalent among those with a disability but it should be noted that around four in ten of those who are hampered by a disability are not reported to have health problems. Socio-emotional difficulties have increased over time among those with a disability, indicating no diminution of need among the group. In addition, depression scores are found to have increased over time for girls with a disability. In contrast, those who have an LLC but are not hampered by it have become more like the non-LLC/disability group over time in their mental health and wellbeing. This suggests that there may now be greater identification of LLCs that do not generally hamper the lives of young people.

DISABILITY AND ADOLESCENT OUTCOMES

Clear differences in adolescent outcomes at age 13 by disability status are evident: young people with an LLC or disability have more conflictual relationships with their parents, smaller peer networks, greater difficulties interacting with peers, less involvement in organised sports and more negative attitudes to school compared to their peers. Across most of the outcomes explored, there remains a substantial gap between those with a disability and those without an LLC/disability in the younger cohort. However, for several of these outcomes, the difference between those with an LLC who are not hampered by it and those without an LLC/disability narrows over time.

Growing numbers of people with an LLC or disability may reflect greater identification of conditions over time or greater need among the population. The findings on wellbeing and other outcomes suggest that both factors are at play. Those not hampered by their condition (non-hampered LLC) come to more closely resemble those without any condition over time in their outcomes, suggesting increased identification of certain conditions. At the same time, however, there is evidence of growing need among those described as having a disability, with increased socio-emotional difficulties and (among girls) depression levels.

IMPLICATIONS FOR POLICY

The study findings point to a significant growth over time in the proportion of 13-year-olds reported to have an LLC or disability. This has consequences for the supports required to enable full inclusion. The most commonly reported difficulties

among those with a disability now relate to physical impairment and difficulties learning, remembering or concentrating, with these impairments having different implications in terms of the resources and supports required. There has been a good deal of policy development in relation to provision for children and young people with a disability, including a greater focus on assessment of need in the early years, a change in the funding allocation model to schools to address special educational needs (SEN), and the marked growth of special classrooms in mainstream schools. While there is now much greater recognition of the need for more inclusive practice, the findings point to a number of areas for further policy development, spanning the areas of education, health, family support and recreational facilities. These include but are not limited to: the targeting of parenting supports towards families of children and teenagers with a disability to help reduce levels of parent–child conflict; school-based efforts to promote social integration with peers and to facilitate improved school engagement; and inclusive practice in out-of-school sport.

CHAPTER 1

Introduction: The measurement of disability prevalence

1.1 BACKGROUND TO THE STUDY

The prevalence of disability among children and young people has attracted increasing policy attention, with recent years seeing a growth in supports such as special needs assistants and a rapid increase in the number of special classes in mainstream schools. This report draws on analyses of the two cohorts of the *Growing Up in Ireland* (GUI) study to unpack trends in the prevalence of disability over a decade. The study was prompted by previous analyses of GUI data (Smyth, 2022, 2024), which showed a significant increase in the number of 9- and 13-year-olds reported to have a long-lasting condition or illness (LLC) or disability. This report seeks to explore changes over time in the proportion of young people with a disability and their profile in terms of gender and family background. In order to examine whether these trends reflect greater identification of conditions over time, we look at the consequences in terms of a number of adolescent outcomes, including socio-emotional difficulties, depressive symptoms, relationships with parents and peers, day-to-day activities and attitudes to school.

Analysis of trends in disability prevalence is complicated by changes in the measures used between GUI cohorts and waves of the survey, which reflect greater awareness of disability over time in society as a whole. The focus has shifted away from the use of diagnostic categories towards an emphasis on the impact of the condition on day-to-day lives, an approach taken in the Census of Population. For this reason, the study does not attempt to look at changes over time in specific conditions; rather the focus is on broad categories of conditions that are comparable between cohorts and over time. The academic and policy literature uses a range of terms. Here, we distinguish between: having a long-lasting condition, illness or disability that does not hamper the child or young person in their day-to-day lives (non-hampered LLC); and disability, namely, having a condition that hampers that child or young person, at least to some extent. Before providing new evidence on the prevalence of disability over time in Ireland in Section 1.4.2, we place the study in the context of international research on disability prevalence and previous measurement of disability among children and young people in Ireland.

1.2 INTERNATIONAL RESEARCH ON TRENDS IN DISABILITY PREVALENCE AMONG CHILDREN AND YOUNG PEOPLE

International studies have emphasised the way in which the size and composition of the group of children and young people with a disability are highly dependent on the definition and measures used (Read et al., 2010; Hagerman and Houtrow, 2020; Panagi et al., 2022). Indeed, several studies have shown a remarkable lack of

overlap among different measures of disability (Parsons and Platt, 2013; Hagerman and Houtrow, 2020; Panagi et al., 2022). The framing of questions is found to make a difference; for example, parents are more likely to report respiratory problems, such as asthma, in response to a list of specified conditions rather than to an open-ended question (Panagi et al., 2022). In Ireland, McConkey et al. (2019) point to considerable variation between Census and administrative estimates of the numbers of children and young people with a disability. Two studies based on GUI data (Banks and McCoy, 2011; Whelan et al., 2021) have estimated much higher rates of disability in early and middle childhood than the Census of Population figures; these studies are described in greater detail in Sections 1.3 and 1.4.1.

Changes in definition and measurement have made it difficult to systematically compare the incidence of disability over time and/or between countries. Furthermore, some large-scale international studies, such as the Programme for International Student Assessment (PISA), exclude a certain proportion of young people with special educational needs (SEN), with the numbers so excluded varying across countries and over time (Brzyska, 2018). However, repeated cross-sectional surveys, mainly in the US, multiple cohort studies in the UK and register data in other countries have provided a basis for drawing some conclusions on trends over time. In the US, Zablotzky et al. (2019) look at 3- to 17-year-olds over the period 2009 to 2017 and indicate significant increases in the proportion with any developmental disability, with an increase for the categories of attention deficit hyperactivity disorder (ADHD), autism spectrum disorder (ASD) and intellectual disability. In Australia, Arabiat et al. (2018) find no overall change in the prevalence of disability among those aged under 14 over the period 2003 to 2015. Using administrative data, Lai et al. (2013) report an increase in overall levels of disability among 3- to 17-year-olds over the period 2000–2011, with the incidence of ASD increasing rapidly. In Northern Ireland, McElroy et al. (2023) found an increase in disability rates among 10- to 19-year-olds over the period 2001–2011 while McConkey (2020) indicated an increase in ASD over the period 2010/2011 to 2018/2019 (from 1.4 to 3.2 per cent).

Many of the existing studies focus on changes in socio-emotional wellbeing or mental health. Comparing two UK cohorts a decade apart, Armitage et al. (2023) point to earlier onset and higher average levels of emotional difficulties among the younger cohort, with especially marked increases for girls.¹ Using the same cohorts, Patalay and Gage (2019) point to an increase over time in depressive symptoms and self-harm among 14-year-olds, as well as higher levels of parent-reported emotional difficulties, conduct problems, hyperactivity and peer problems, measured using the Strengths and Difficulties Questionnaire (SDQ). Taking a broader span of UK cohort data, McElroy et al. (2023) found an increase in emotional problems for both sexes but more variable trends for behavioural

¹ Measured using the SDQ subscale.

problems. Their analyses indicate these patterns are not artefacts of measurement error. Emotional or psychological difficulties also increased in prevalence among under 14s in Australia over the period 2003–2015 (Arabiat et al., 2018), in Wales among 11- to 16-year-olds over the period 2013–2019 (Anthony et al., 2023) and in Sweden among 15-year-olds over the period 1998–2008 (Durbeej et al., 2019). In the US, the prevalence of major depressive episodes among 12-to-17-year-olds almost doubled during the period 2009–2019, with a greater increase for girls and for those aged 12 to 14 years (Daly, 2022). Similarly, Nilsen et al. (2024) found an increase in adolescent depressive symptoms in Norway over the period 2010 to 2019, particularly for girls. They indicate that these trends are not an artefact of changes in reporting behaviour. Another Norwegian study (Potrebny et al., 2024) traces these patterns further back, indicating a clear increase in mental health problems among females since the early 1990s. In Ireland, the My World Surveys (Dooley et al., 2019) indicated a significant increase in levels of depression and anxiety among adolescents between 2011/2012 and 2018/2019, with particular increases for females.

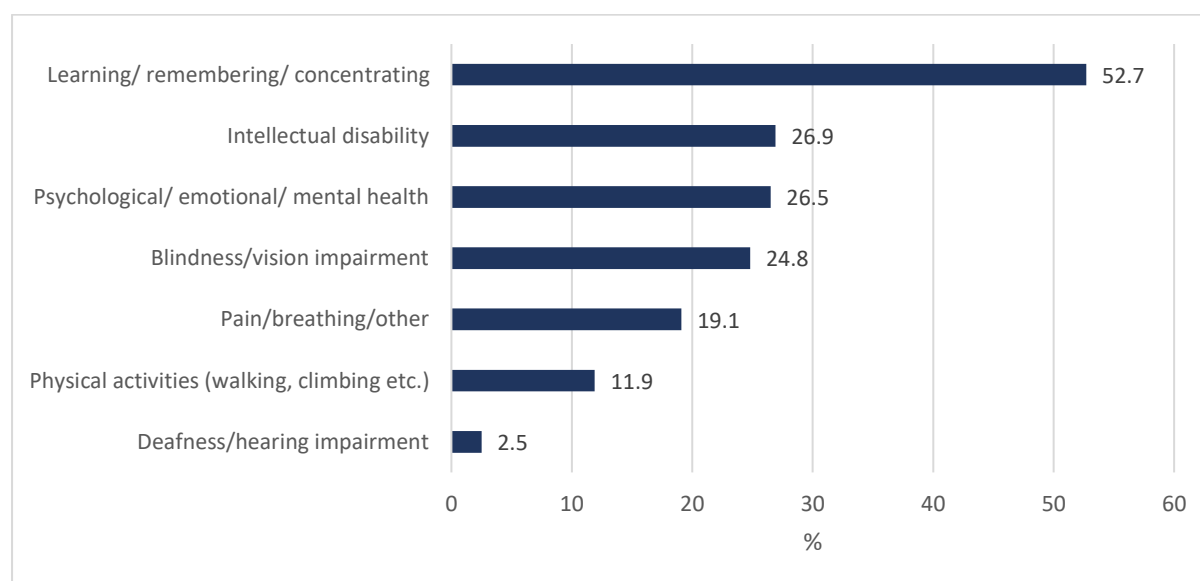
Not all studies point to declining mental health and wellbeing among children and young people. An American study showed no significant increase in emotional symptoms, conduct problems or hyperactivity between 2004 and 2019 (Riehm and Mojtabai, 2022). In a German study, the level of problematic SDQ scores for total socio-emotional difficulties among 11- to 17-year-olds remained stable over a ten-year period (Baumgarten et al., 2023). A Dutch study showed a decline in emotional wellbeing (again measured using the SDQ) between 2009 and 2013, linked to increased schoolwork pressure, but relative stability in the subsequent four years (De Looze et al., 2020).

In sum, the prevalence of disability varies according to the definition used, making it difficult to compare countries or cohorts of young people. There is a body of research that points to increased socio-emotional or mental health difficulties over time, especially among girls. It is worth noting, however, that these studies predate the COVID-19 pandemic, which has been shown to have led to a decline in psychological wellbeing and an increase in mental health problems among children and adolescents (see, for example, Wolf and Schmitz, 2024, for a systematic review). Discussions of changes in the prevalence of disability have taken place against a shifting backdrop in how disability is framed. Increasingly, the so-called medical model, which focuses on diagnostic categories, has been criticised as a deficit-based perspective. In contrast, the social model posits that disability is a social construct, reflecting a mismatch between individual needs and their environment (see, for example, Fovet, 2023).

1.3 EXISTING MEASURES OF DISABILITY AMONG CHILDREN AND YOUNG PEOPLE IN IRELAND

In Census 2022, the identification of disability is based on two questions: whether the person experiences a long-lasting condition or difficulty; and whether, as a consequence of this condition, they have difficulty with day-to-day or work tasks. Those who reported any difficulties in either question were counted as having a disability. Census 2022 figures indicate that 12 per cent of 9-year-olds and 14 per cent of 13-year-olds were reported to have a disability. At both ages, rates were higher for males than for females, though the gender gap was somewhat narrower at 13 than at 9 (15.8 vs. 12.5 per cent at 13; 14.7 vs. 9.5 per cent at 9). Figure 1.1 shows the types of conditions or difficulties as a percentage of 13-year-olds with a disability. The main difficulties relate to learning or psychological difficulties, with over half reported to have difficulties in learning, remembering or concentrating. One-quarter are reported to have a vision impairment, though this group is indicated as being affected to some extent rather than to a great extent, presumably including conditions that can be corrected.

FIGURE 1.1 TYPES OF CONDITIONS OR DIFFICULTIES AS A PERCENTAGE OF 13-YEAR-OLDS WITH A DISABILITY, CENSUS 2022



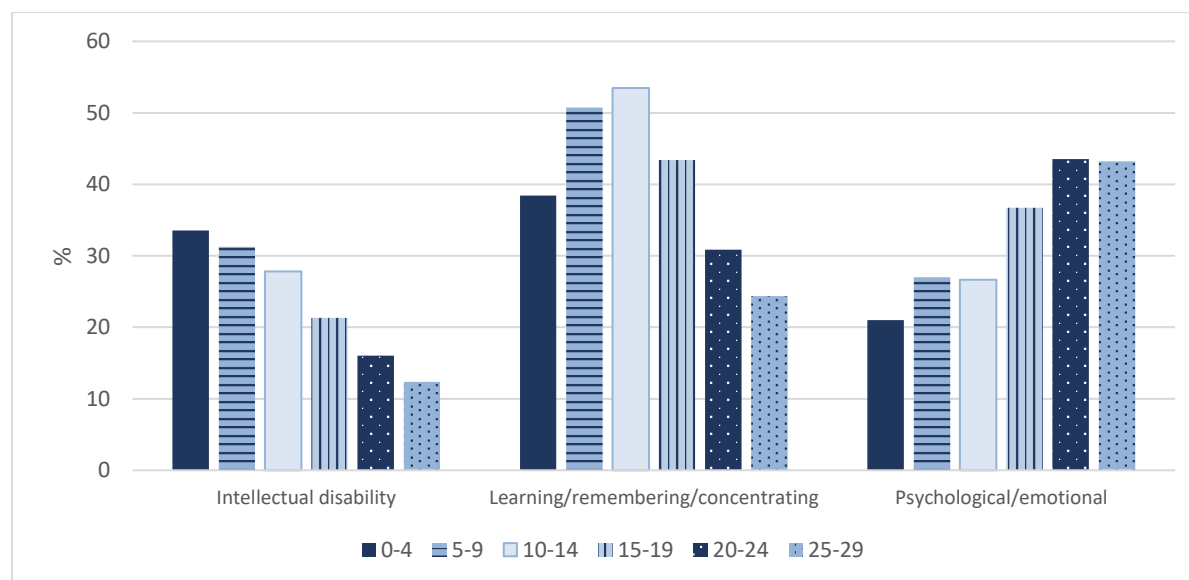
Source: Census 2022.

Note: Totals add to more than 100 per cent because multiple difficulties can be indicated.

However, the Census data provide interesting insights into the prevalence of certain conditions by age group. Physical difficulties are more common among older age groups (not shown here). Among children and young people with a disability, the majority have difficulties in learning, remembering or concentrating, or psychological, emotional or mental health difficulties (Figure 1.2). Difficulties in learning, remembering or concentrating make up a large proportion of those aged 5 to 14 years (as a proportion of those with a disability and also in terms of absolute numbers, not shown here). Emotional or mental health difficulties account for a

greater proportion of conditions among those aged 15 to 19 years, with a further increase into the twenties. These figures cannot indicate whether the patterns relate to greater identification of conditions among young people or increased levels of need among these age groups.

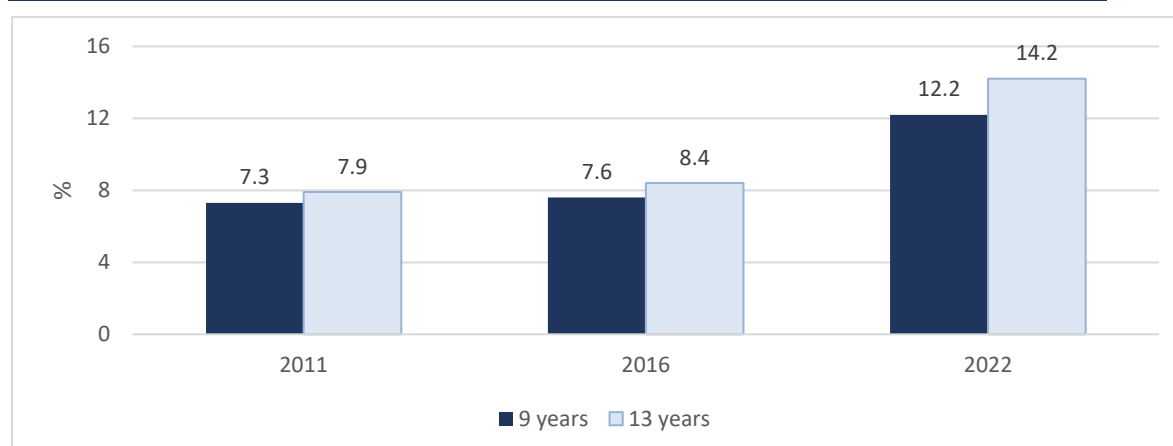
FIGURE 1.2 PROPORTION OF THOSE WITH SELECTED CONDITIONS AMONG THOSE WITH A DISABILITY BY AGE, CENSUS 2022



Source: Census 2022.

The Census statistical releases caution against looking at trends over time, because of changes in the question format. Nonetheless, the figures do point to an increasing prevalence of disability over time among 9- and 13-year-olds (Figure 1.3).² Furthermore, there is evidence at all three time-points of increasing identification or emergence of need between 9 and 13 years of age.

² This appears to be a longer-term trend, with disability prevalence increasing from 4.2 to 6.1 per cent among 5- to 9-year-olds and 5.8 to 7.7 per cent among 10- to 14-year-olds between 2006 and 2011.

FIGURE 1.3 CENSUS ESTIMATES OF PERCENTAGE OF 9- AND 13-YEAR-OLDS WITH A DISABILITY, 2011–2022

Source: Census 2011, 2016 and 2022.

Available administrative data in Ireland generally focus on those in receipt of services, rather than the broader group with long-lasting conditions. Under the 2005 Disability Act, an assessment of need identifies a child's health needs and the services required to meet those needs. The proportion of those who were assessed under this statutory assessment of need process as having an autism diagnosis increased from 29 per cent of those with an identifiable condition in 2015 to 54 per cent in 2022.³ Similarly, autism prevalence among school-leaver applicants for disability day services increased from 35 per cent in 2019 to 52 per cent in 2023. Between 2014 and 2021, the number of students attending special classes at primary level increased by 129 per cent (to 8,740) and by 205 per cent (to 3,178) at second level (Department of Education, 2023; NCSE, 2024). National Council for Special Education (NCSE) figures indicate that the most common designation for special classes is for ASD or ASD early intervention. Health Research Board (HRB) data for people engaging with disability services (registered on the National Ability Supports System) included 45,068 children and young people in 2022 (3.5 per cent of all those aged under 18).⁴ Of these, 39 per cent had autism as a primary disability, 24 per cent had an intellectual disability and 6 per cent had a physical disability.

McConkey et al. (2019) highlighted the challenges in identifying the prevalence of intellectual disability and pointed to much higher numbers identified by the Census than by administrative data (the National Intellectual Disability Database, NIDD). In 2011, the Census identified 1.8 times more children than were registered on the

³ We are very grateful to Eithne Fitzgerald, DCEDIY, for access to these and other figures quoted in this section.

⁴ See <https://www.hrb.ie/data-collections-evidence/disability-service-use-and-need/latest-data/>.

NIDD, and 2.35 times more in 2016. This reflects the fact that not all children with an intellectual disability require specialist services.

1.4 DISABILITY PREVALENCE USING *GROWING UP IN IRELAND* DATA

1.4.1 Previous research using GUI data

To date, two studies have used GUI data to derive estimates of the proportion of children with disabilities or additional needs. Both studies indicated estimates higher than those given by the Census. Banks and McCoy (2011) used GUI data to estimate the number of children with a SEN, reflecting the broad definition of SEN used by the Education for Persons with Special Educational Needs (ESPSEN) Act 2004. Based on 9-year-olds from GUI Cohort '98, this definition included: those identified as having physical, speech, learning and emotional/behavioural disabilities by their teacher; those identified by their mother as having a learning difficulty or communication or coordination disorder, speech difficulties or a physical or mental health problem, illness or disability that hampered their daily activities; and those rated as having high levels of socio-emotional difficulties (being in the top ten per cent on the SDQ total difficulties scale), as reported by teachers. The study pointed to an overall prevalence of 25 per cent, with higher SEN levels among boys than girls.⁵

Whelan et al. (2021) used GUI Cohort '08 data on 5-year-olds, basing estimates on teacher reports of limitations affecting the child at school. Their estimate of prevalence was 8.8 per cent compared to 4.5 per cent for the 2016 Census. Including speech difficulty or mild general learning difficulty increased the estimate to 15.5 per cent. In particular, the GUI estimates for intellectual disability, difficulty with learning, remembering or concentrating and psychological/emotional conditions were higher than estimates based on Census data.

1.4.2 New estimates of changes in prevalence over time

This study uses GUI data from Cohorts '98 and '08 to derive estimates of changes in the prevalence of LLCs and disabilities among young people over time. Fieldwork for Cohort '98 at 13 years of age took place on a face-to-face basis over the period of August 2011 to February 2012, with a response rate of 90 per cent of the valid sample (Thornton et al., 2016). Reflecting continuing public health restrictions at the time (July 2021 to June 2022), fieldwork for Cohort '08 at 13 years of age was conducted via telephone, with the self-complete element (on sensitive topics like depression) administered via an online platform hosted by the Central Statistics Office (CSO) (Murray et al., 2023). The response rate was 78 per cent of the valid sample (Murray et al., 2023). In both survey waves, attrition was greater among

⁵ Using a slightly different classification on the same data, Cosgrove et al. (2014) estimated the proportion of 9-year-olds with a SEN to be 28 per cent.

more socio-economically disadvantaged groups, so weighting is used to make the samples representative of the population as a whole.

TABLE 1.1 MEASURES OF LONG-LASTING CONDITIONS, DISABILITY AND SPECIAL EDUCATIONAL NEEDS OVER WAVES AND COHORTS

	Cohort '98	Cohort '08
At age 9: Long-lasting condition	Does the study child have any ongoing chronic physical or mental health problem, illness or disability? If yes, is the study child hampered in his/her daily activities by this problem, illness or disability?	Does the child have any longstanding illness, condition or disability? By longstanding I mean anything that has troubled him/her over a period of time or that is likely to affect him/her over a period of time? If yes, do any of these illnesses hamper the child in his/her daily activities?
At age 13: Long-lasting condition (open)	Does the child have any ongoing chronic physical or mental health problem, illness or disability? If yes, whether hampered in their daily activities.	
Long-lasting condition (list)	Does the child have any of the following conditions or disabilities?	Does the child have any of the following long-lasting conditions or difficulties? If yes, whether hampered in their daily activities.
At age 9 only (teacher report): Special educational needs	Do any of the following limit the kind or amount of activity the study child can do at school?	Do any of the following limit the kind or amount of activity the study child can do at school?

Source: GUI Cohorts '98 and '08. Age 9 interviews were carried out in 2007/2008 and 2017/2018 respectively. Age 13 interviews were carried out in 2011/2012 and 2021/2022 respectively.

Table 1.1 outlines the measures used in both cohorts for those aged 9 and 13 years of age, while Table 1.2 shows measures of the types of conditions. Two sets of information are used to derive the main measures employed in the remainder of the report. Firstly, at age nine, whether the child or young person has an ongoing or long-standing illness or disability is measured by answers given by primary caregivers (hereafter, termed mothers) to the open question on whether the child has such a condition. At age 13, mothers in Cohort '98 were asked a similar open question about ongoing conditions, but were also asked whether the child had any of a list of conditions or disabilities. Mothers in Cohort '08 were only asked whether

their child had any of the list of conditions, and the list was slightly different from that used for Cohort '98, reflecting the terminology used in Census 2022. Secondly, mothers were asked about the extent to which their child was hampered in their day-to-day lives by that condition.

These measures were used to distinguish between the following groups:

1. 'Non-hampered LLC' – those who have a long-lasting condition but are not hampered by it.
2. 'Disability' – those who have a long-lasting condition and are hampered by it, at least to some extent.

For reasons of comparability, the 'list' measure is used for both cohorts to capture having an LLC at age 13.⁶

A measure of having a SEN, as reported by the primary teacher, is also included in this chapter for comparative purposes. It is based on the child being limited in their activities at school because of one of a list of conditions. This measure is only available at age 9 as teachers were not surveyed for the 13 year wave.

The measure of disability used in this study does not replicate that derived by Banks and McCoy (2011) for two reasons. First, the primary focus of the study is on 13-year-olds and the lack of teacher reports at this wave means we cannot triangulate information from parents and teachers. Second, we are interested in looking at changes over time, so using a relative measure of socio-emotional difficulties (top 10 per cent of SDQ) would constrain such a comparison.

⁶ As noted above, the disability question (whether the young person is hampered by their condition) at age 13 for Cohort '98 is filtered through responses to the open question. This makes the disability group a smaller subgroup of those with LLC.

TABLE 1.2 MEASURES OF TYPES OF CONDITIONS OVER WAVES AND COHORTS

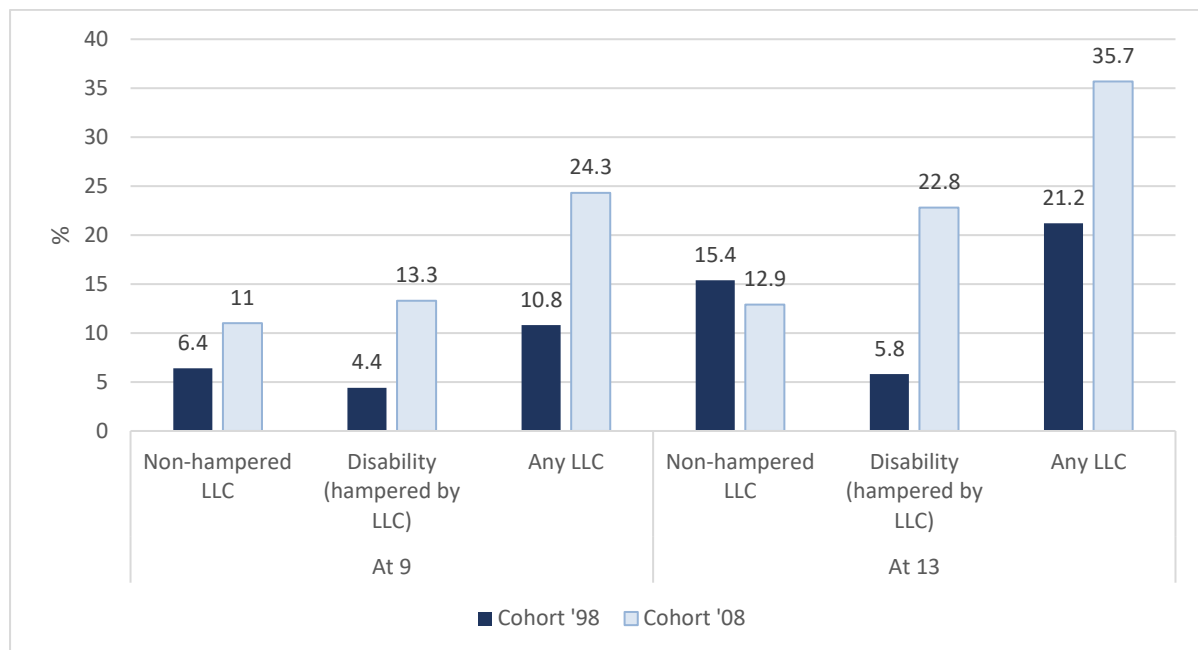
	Cohort '98	Cohort '08
At age 9: Long-lasting condition	ICD-10 codes – 14 categories mainly framed as 'diseases of ...' with one category for 'mental and behavioural disorders'.	Coded into 23 conditions and an 'other' category – mixture of 'a problem with...' and named conditions.
At age 13: Long-lasting condition (open)	ICD-10 codes – 14 categories mainly framed as 'diseases of...' with one category for 'mental and behavioural disorders'.	
Long-lasting condition (list)	List of 8 conditions and an 'other (please specify)' option.	List of eight difficulties and an 'any other' category. Adapted version of Census 2022 wording and differs from Cohort '98. Also asked, what is the nature of this condition or difficulty? ICD-10 codes.
At age 9 only (teacher report): Special educational needs	Four conditions and other; uses term 'learning disability'.	Seven conditions and other; separates out into specific, general: mild and general: moderate/ severe/ profound; ASD.
Challenge across cohorts	Small number in many categories (often too small to report); 'mental/behavioural' category not well differentiated.	

Source: GUI Cohorts '98 and '08.

Note: ICD: International Classification of Diseases.

Table 1.2 indicates significant change in the definitions used to measure types of impairments or conditions between cohorts and between survey waves, reflecting changes in awareness and use of terminology over time. The International Classification of Diseases (ICD) classification is used at age 13 in both cohorts but the small number in many categories means that we cannot report several of these groups. Furthermore, the 'mental/behavioural' category is not well differentiated.

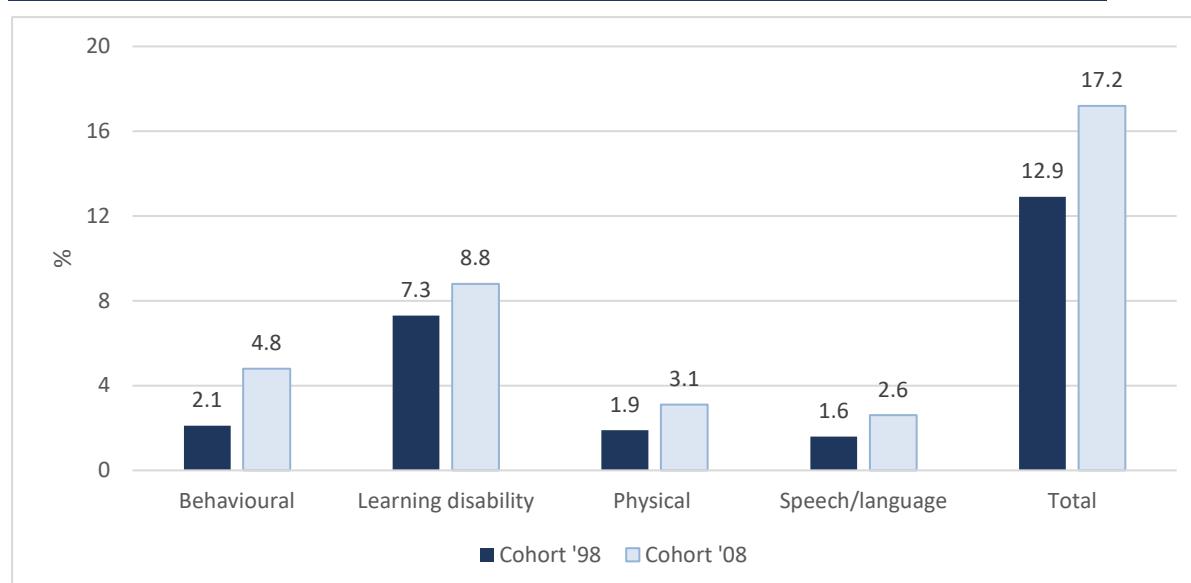
FIGURE 1.4 PREVALENCE OF LONG-LASTING CONDITIONS AT 9 AND 13 YEARS OF AGE, DISTINGUISHING BETWEEN THOSE WHO ARE AND ARE NOT HAMPERED BY THAT CONDITION, AS REPORTED BY MOTHERS



Source: GUI Cohorts '98 and '08

Figure 1.4 shows the prevalence of having an LLC at ages 9 and 13, distinguishing between those who are hampered by that condition (disability) and those who are not (non-hampered LLC). The figures show a very significant increase in reported prevalence of any condition between cohorts (over a decade) – from 11 to 24 per cent at age 9 and from 21 to 36 per cent at age 13. There is also an increase in prevalence as children get older (by 10 percentage points for Cohort '98 and 11 percentage points for Cohort '08). This reflects a growing identification of need and/or emerging conditions. It should be noted that the framing of questions makes a difference. At age 13 (in Cohort '98), 21 per cent of mothers reported that their child has one of a list of conditions, but when asked an open question about long-standing conditions, the reported prevalence is lower, at 11 per cent.

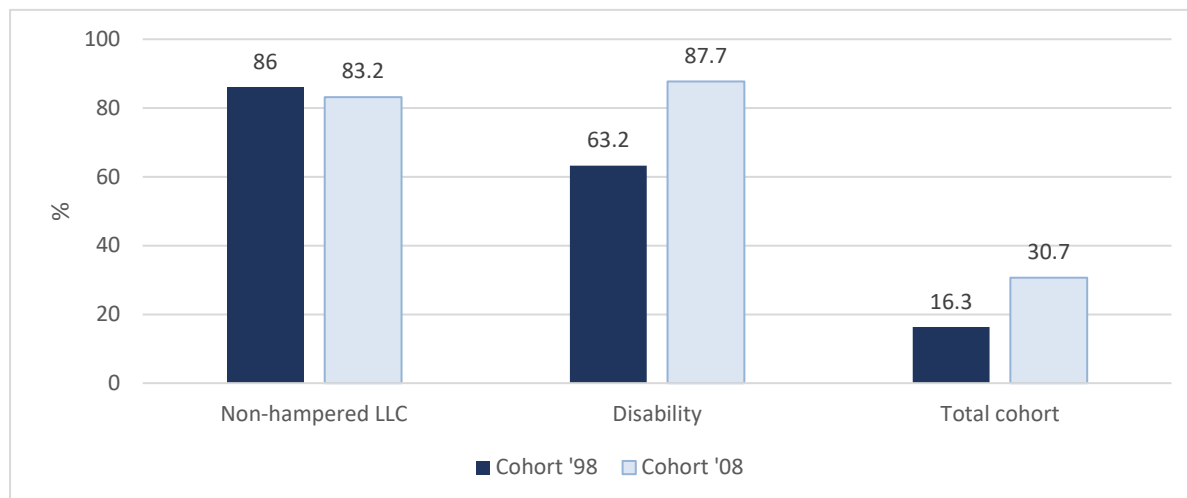
There is a marked increase over time in those who have a disability (that is, a condition by which they are hampered): from 4 per cent for Cohort '98 to 13 per cent for Cohort '08 at age 9, and from 6 per cent for Cohort '98 to 23 per cent for Cohort '08 at age 13. Disability increases markedly with age for Cohort '08 (from 13 to 23 per cent) but growth between 9 and 13 years is much more modest for Cohort '98.

FIGURE 1.5 PREVALENCE OF SPECIAL EDUCATIONAL NEEDS AT 9 YEARS OF AGE, AS REPORTED BY TEACHERS

Source: GUI Cohorts '98 and '08.

As discussed above, teacher-reported SEN measures are only available at age nine. Prevalence increases from 13 per cent for Cohort '98 to 17 per cent for Cohort '08 (Figure 1.5). Increases are evident across all of the categories listed, though are most marked for behavioural difficulties. The results show that the prevalence of disability or SEN depends on the definition used as well as the informant involved: just under half (49 per cent) of those reported to have a disability by their mother are reported to have a SEN by their primary teacher. This likely reflects the interaction between individual need and the environment, in keeping with the social model of disability. In this way, a young person may be hampered in relation to a particular domain, such as school engagement but not in another, for example, peer relationships.

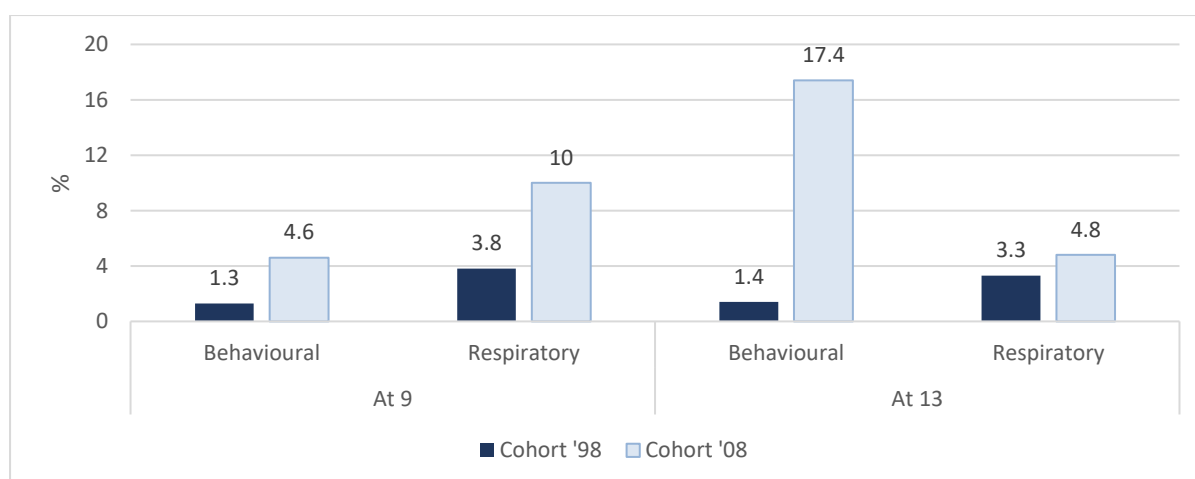
FIGURE 1.6 PROPORTION OF 13-YEAR-OLDS WITH A LONG-LASTING CONDITION THAT HAVE BEEN DIAGNOSED WITH ONE OR MORE CONDITIONS BY COHORT



Source: GUI Cohorts '98 and '08.

As well as being asked about the presence of conditions, mothers were asked about whether their child had received a diagnosis for that condition. The proportion of the total cohort who had received at least one diagnosis increased from 16 per cent for Cohort '98 to 31 per cent for Cohort '08 (Figure 1.6). Over four-fifths of the non-hampered LLC group had received a diagnosis in both cohorts. In contrast, the proportion of those who had a disability with a diagnosis increased over time, from 63 to 88 per cent.

FIGURE 1.7 TYPES OF LONG-LASTING CONDITION (LARGEST GROUPS) AS PERCENTAGE OF TOTAL POPULATION (WITH AND WITHOUT A LONG-LASTING CONDITION)

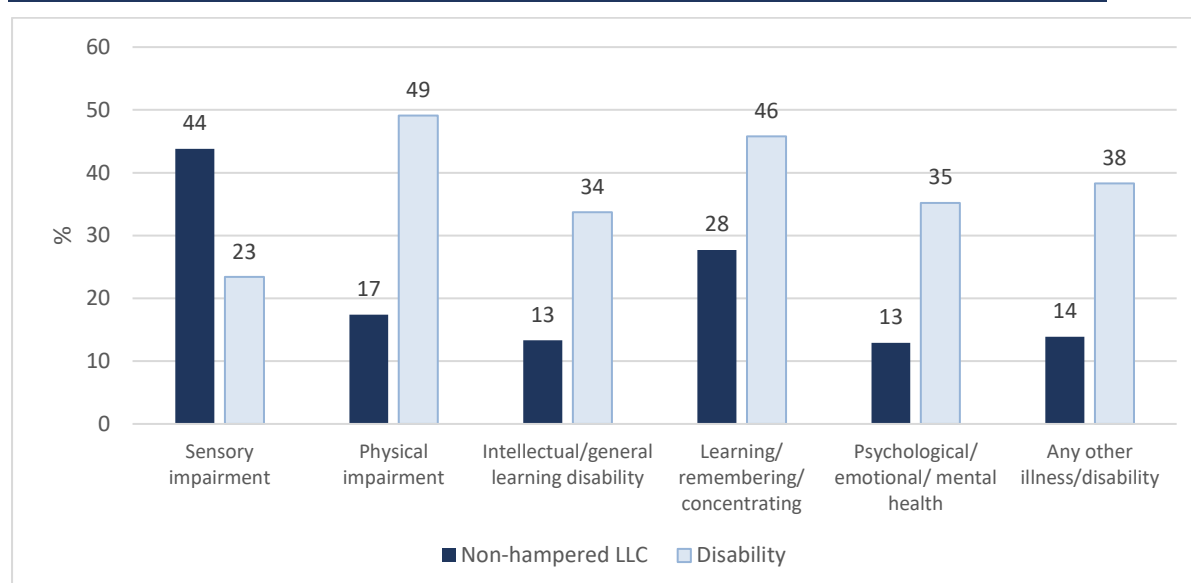


Source: GUI Cohorts '98 and '08.

Figure 1.7 refers to the two largest groups of LLC. The small sample size here means it is not possible to break this down in detail between those who are hampered by that condition (i.e. those with a disability) and those who are not. The figures show

an increase in both respiratory and behavioural difficulties over time. The increase is particularly marked for behavioural difficulties, increasing from 1 to 17 per cent between cohorts at age 13. This compares to an increase from 3 to 5 per cent for respiratory problems. Furthermore, the pattern between 9 and 13 years is stable for Cohort '98 but increases markedly for Cohort '08. Looking at those with emotional/behavioural disability separately (not shown in figure), this is found to have increased from 1.1 per cent of the total cohort in Cohort '98 to 13.5 per cent in Cohort '08.

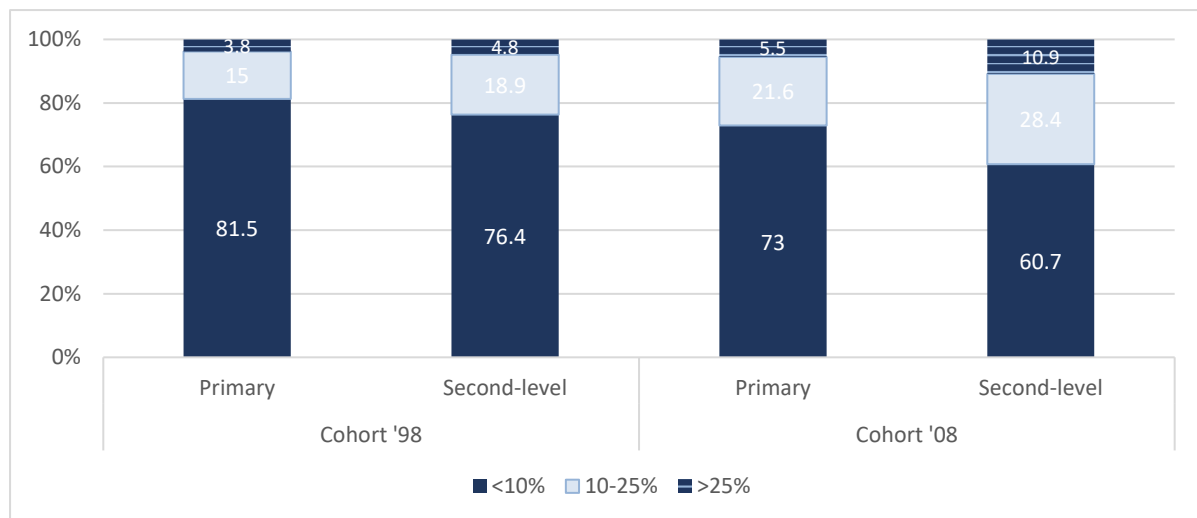
FIGURE 1.8 TYPE OF CONDITION OR DIFFICULTY AS A PROPORTION OF THOSE IN THE NON-HAMPERED LONG-LASTING CONDITION AND DISABILITY GROUPS, 13-YEAR-OLDS OF COHORT '08



Source: GUI Cohorts '98 and '08.

Note: Percentages total to more than 100 as more than one condition or difficulty can be reported.

Figure 1.8 shows the types of conditions or difficulties at age 13 present among Cohort '08 members; these data are provided as a proportion of those who have an LLC (but are not hampered by it) and of those with a disability. The figure shows, for example, that those with a sensory impairment make up 44 per cent of the non-hampered LLC group but make up just 23 per cent of the smaller group with a disability. Comparable figures cannot be provided for Cohort '98 because of changes in question wording. Among the non-hampered LLC group, the largest categories are those with a vision or hearing impairment (44 per cent of this group) and those with difficulties learning, remembering or concentrating (28 per cent). Among those with a disability (i.e. those hampered to at least some extent by that condition), the largest groups are physical impairment (49 per cent) and difficulties learning, remembering or concentrating (46 per cent).

FIGURE 1.9 PREVALENCE OF EMOTIONAL AND BEHAVIOUR DIFFICULTIES IN THE SCHOOL, AS REPORTED BY SCHOOL PRINCIPALS

Source: GUI Cohorts '98 and '08.

Information on the prevalence of emotional and behavioural difficulties in the school was reported in the GUI principal survey, providing another source of information on potential changes over time. Among primary schools, there is an increase in the proportion of schools indicating a prevalence of 10 per cent or more, from 19 per cent for Cohort '98 to 27 per cent for Cohort '08 (Figure 1.9). Among second-level schools, the proportion increases from 24 per cent to 39 per cent. Over 10 per cent of principals now report that one-quarter or more of their students have emotional and behavioural difficulties.

1.5 CONCLUSIONS

This chapter has outlined the prevalence of LLCs and disabilities among young people in Ireland, using GUI data. The data point to a marked increase occurring over the decade in question: the proportion having an LLC (whether or not they are hampered by it) at age 13 increased from 24 to 36 per cent. In the same period, the proportion having a disability (that is, were hampered by that condition) grew from 6 to 23 per cent. These trends are based on information provided by the mothers of study children, but teacher and principal reports also indicate an increase in prevalence over time. As with previous GUI-based studies (Banks and McCoy, 2011; Whelan et al., 2021), these figures are higher than the Census estimates for disability for comparable age groups, though Census figures have also shown an upward trend over time.

Changes in the measures used over time make it challenging to look at trends in types of conditions in a systematic way. The onset of the pandemic before the age 13 wave data collection for Cohort '08 further complicates the picture. Nonetheless, the analyses point to a significant shift in the prevalence of emotional/behavioural disabilities: from 1 to 17 per cent of 13-year-olds over a 10-

year period. The scale of the shift in just a decade raises questions as to whether the figures reflect an increase in identification or an increase in underlying need. The following chapters seek to address this issue by looking at the overlap between LLC/disability and other measures of health and wellbeing, and by examining selected adolescent outcomes by disability status. Changes may reflect identification; that is, a young person with a particular condition may be more likely to be diagnosed in a later cohort than previously. Alternatively, changes may indicate a growth in the prevalence over time of a condition, such as depression, that hampers a young person's day-to-day activities. If the main driver is increased identification, we expect that the profile of those with an LLC or disability would become more heterogeneous over time, meaning fewer differences by disability status among the younger cohort.

CHAPTER 2

Trends in the profile of young people with disabilities

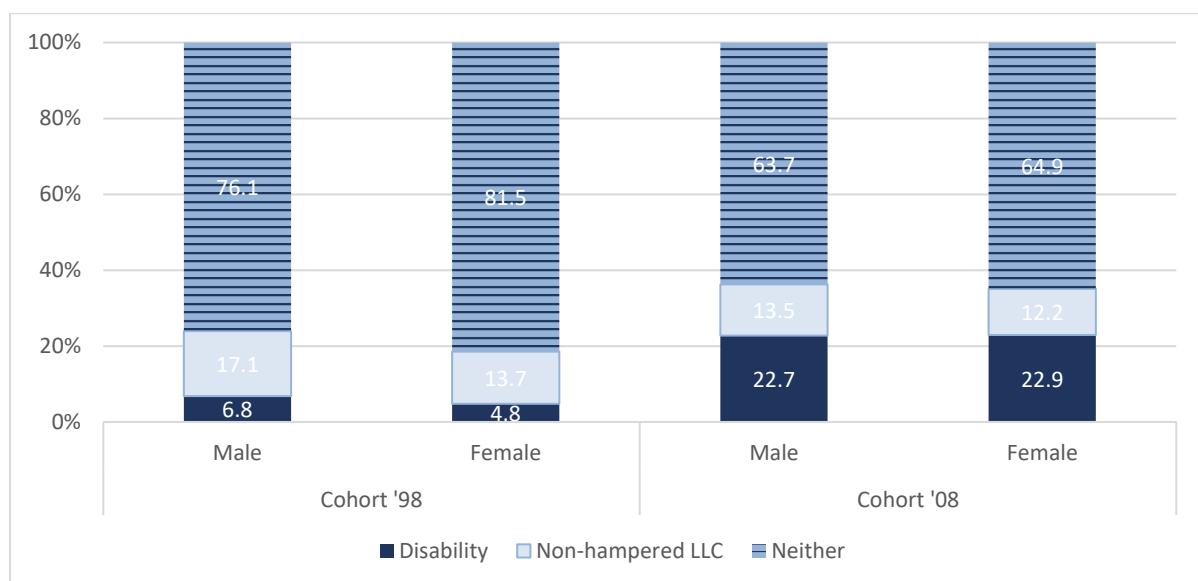
2.1 INTRODUCTION

This chapter looks at potential changes over time in the profile of young people with long-lasting conditions or disabilities and the extent to which having a long-lasting condition (LLC) or disability overlaps with other aspects of wellbeing measured at age 13. Section 2.2 examines changes in the socio-demographic profile of young people with an LLC or disability, while Section 2.3 explores levels of physical health, socio-emotional and mental health difficulties by disability status.

2.2 SOCIO-DEMOGRAPHIC PROFILE

Chapter 1 has outlined the increase in the proportion of young people reported as having an LLC or disability across cohorts. As indicated in Chapter 1, the analyses distinguish between those who have a long-lasting condition but are not hampered by it (non-hampered LLC) and those who are hampered by their condition (disability). Figure 2.1 shows the gender breakdown of these groups. Among Cohort '98, boys were significantly more likely to be identified as having an LLC or disability than girls. However, a decade later, no significant gender differences are evident.

FIGURE 2.1 DISABILITY STATUS AT AGE 13 BY GENDER AND COHORT



Source: GUI Cohorts '98 and '08.

Table 2.1 looks at the range of individual and family background factors associated with disability status. These analyses pool data from the two cohorts, while later

analyses directly test whether the relationship between these factors and disability status changes over time. The model is a multinomial logit, with the chances of having an LLC or disability compared to those with neither condition. The coefficients are presented in terms of relative risk ratios,⁷ with values greater than one indicating increased chances of having a disability/LLC and values less than one being associated with reduced chances.

Even controlling for a shift in the profile of young people and their families over time, there has been a significant growth in the proportion identified as having a disability. Disability status does not vary markedly by parental education, but those from professional, managerial or other non-manual groups are less likely to be identified as having a disability than other social classes. Those from a lone-parent family, those living in rented accommodation (either social housing or the private rented sector) and those living in urban areas are more likely to have a disability than others, while those from migrant-origin families are less likely to have an LLC or disability than their Irish-origin peers.

⁷ Average marginal effects (AMEs) are not presented to ensure comparability with the tables including interaction terms; AMEs cannot be derived for models including interaction terms.

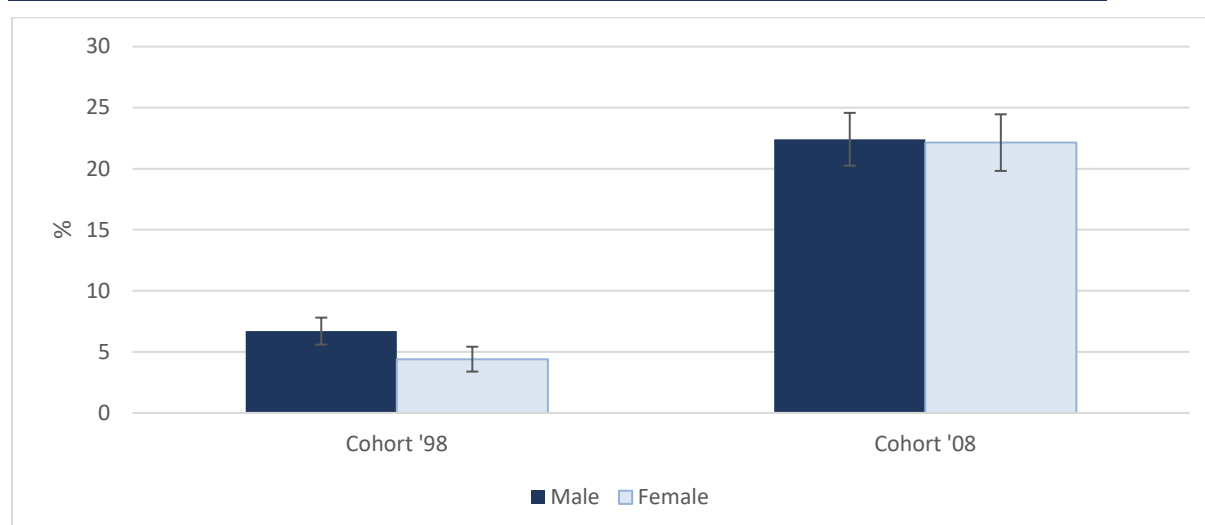
TABLE 2.1 MULTINOMIAL LOGIT MODEL OF FACTORS ASSOCIATED WITH DISABILITY STATUS (RELATIVE RISK RATIOS) (BASE CATEGORY: NO LONG-LASTING CONDITION OR DISABILITY)

	Has an LLC but is not hampered	Disability (hampered)
Constant	0.252	0.091
Cohort '08	1.054	4.910***
Female	0.782**	0.837*
Parental education:		
Leaving Certificate	0.792	0.867
Post-secondary	0.942	0.948
Degree or higher (Ref. Junior Certificate or lower)	0.763±	0.920
Household social class:		
Professional	0.749±	0.679*
Managerial	0.916	0.640**
Other non-manual	0.856	0.701*
Skilled manual	1.051	0.895
Non-employed household (Ref.: Semi/unskilled manual)	1.376±	1.145
Migrant-origin family	0.758*	0.679**
Lone-parent family	1.208	1.440**
Large family (3 or more children)	1.027	0.865
Living in urban area	1.051	1.183*
Living in rented accommodation (social or private)	1.046	1.445**
Pseudo R²	0.057	
N	13,540	

Source: GUI Cohorts '98 and '08, age 13 wave.

Notes: *** significant at the p<.001 level, ** p<.01, * p<.05, ± p<.10.

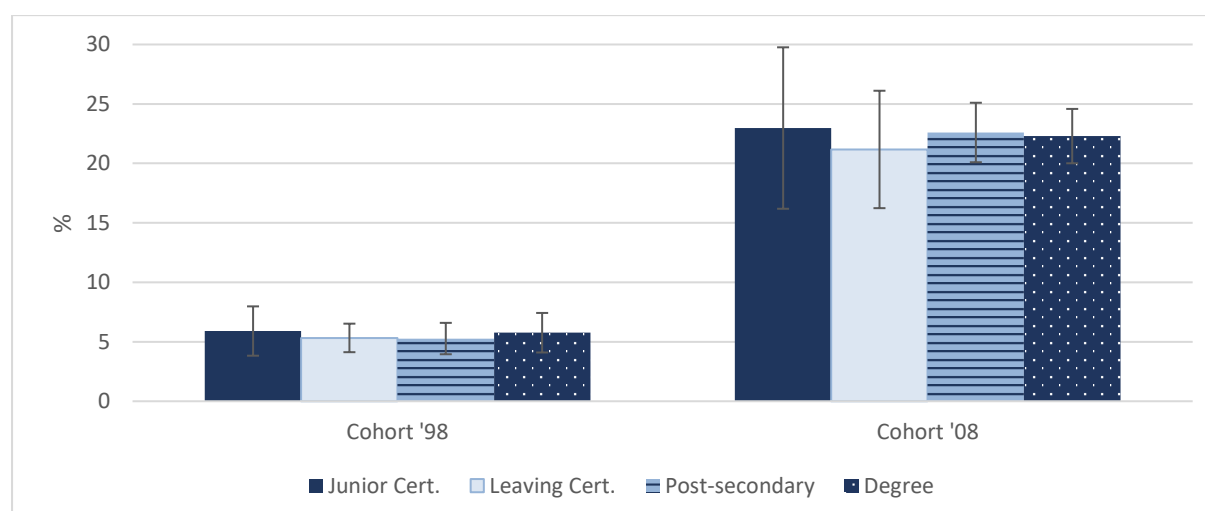
Examining the interaction between background factors and cohort allows us to analyse whether the patterning of relationships has changed between cohorts. Figure 2.2 depicts the interaction between gender and cohort. In keeping with the descriptive picture presented in Figure 2.1, there is a higher prevalence of disability among boys than girls in Cohort '98, though in Cohort '08, this difference has disappeared.

FIGURE 2.2 PREDICTED PERCENTAGE WITH A DISABILITY BY GENDER AND COHORT

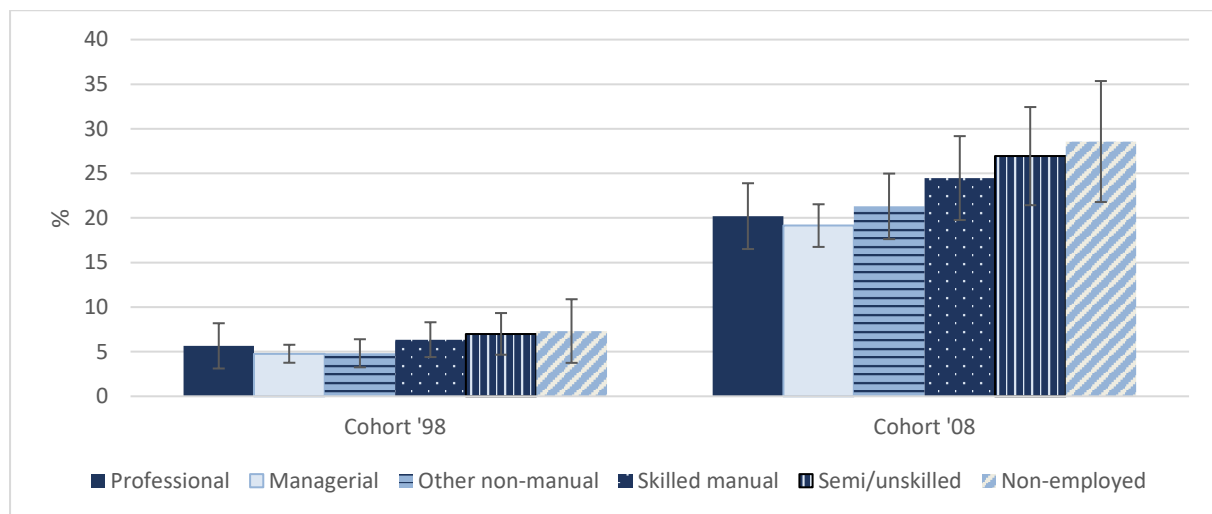
Source: Derived from models in Table 2.1 with interaction term included.

Note: The 95 per cent confidence intervals do not overlap for Cohort '98 but do for Cohort '08.

There is little systematic variation in disability status by parental education and this relationship does not change over time, with disability prevalence increasing for all education groups (Figure 2.3). Similarly, growth in prevalence was evident across all social class groups (Figure 2.4). While there appeared to be less relative increase among the professional group, the overlapping confidence intervals indicate this difference is not statistically significant.

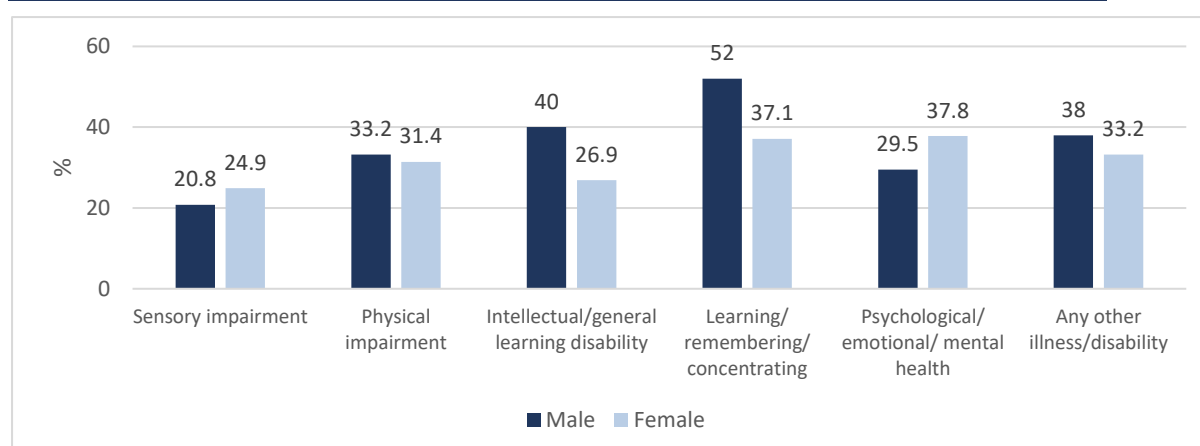
FIGURE 2.3 PREDICTED PERCENTAGE WITH A DISABILITY BY PARENTAL EDUCATION AND COHORT

Source: Derived from models in Table 2.1 with interaction term included.

FIGURE 2.4 PREDICTED PERCENTAGE WITH A DISABILITY BY SOCIAL CLASS AND COHORT

Source: Derived from models in Table 2.1 with interaction term included.

In sum, there has been a growth in disability prevalence across all social groups in terms of parental education and class, but a greater increase in prevalence among girls than boys. This has resulted in there being no significant gendering of disability rates among Cohort '08. While overall levels of disability are broadly similar for boys and girls in Cohort '08, significant differences are evident in the types of difficulties or conditions reported. Boys are significantly more likely than girls to have an intellectual or general learning disability, to experience difficulties learning, remembering or concentrating, and, to some extent, to have any other illness/disability (Figure 2.5). They are also more likely to have multiple difficulties than girls. Girls are slightly more likely to have a sensory impairment but are much more likely than boys to have a psychological, emotional or mental health difficulty. Because of changes in the type of condition captured between cohorts (see Chapter 1), it is difficult to determine which conditions have increased more in girls over time. However, the patterns suggest that increased emotional or mental health difficulties among girls may underlie this gender shift (see Section 2.3 for further detail on levels of socio-emotional difficulties and depression).

FIGURE 2.5 TYPE OF CONDITION AMONG THOSE WITH A DISABILITY (THAT IS, HAMPERED BY THAT CONDITION) BY GENDER, COHORT '08

Source: GUI Cohort '08.

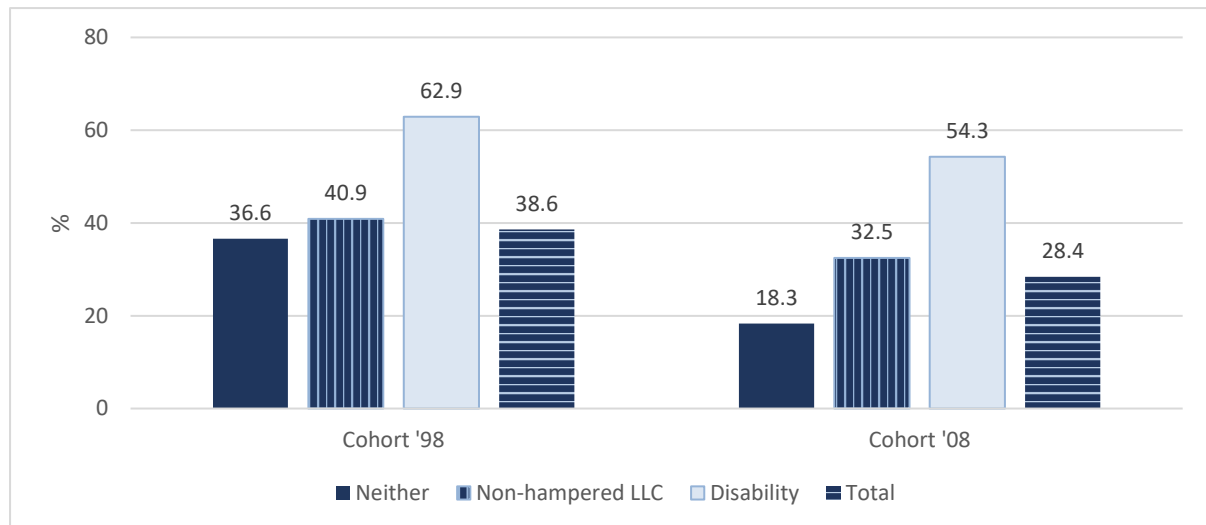
Note: Percentages total to more than 100 as more than one condition or difficulty can be reported.

2.3 HEALTH AND WELLBEING BY DISABILITY STATUS

This section looks at the extent of overlap between disability status and three measures of health and wellbeing at age 13: physical health, as reported by the young person's mother; depressive symptoms, as reported by the young person; and socio-emotional difficulties, as reported by the mother. If identification of those with an LLC or disability has increased over time (without any shift in the underlying conditions), then we would expect that the differences between those with an LLC/disability and others would reduce between cohorts.

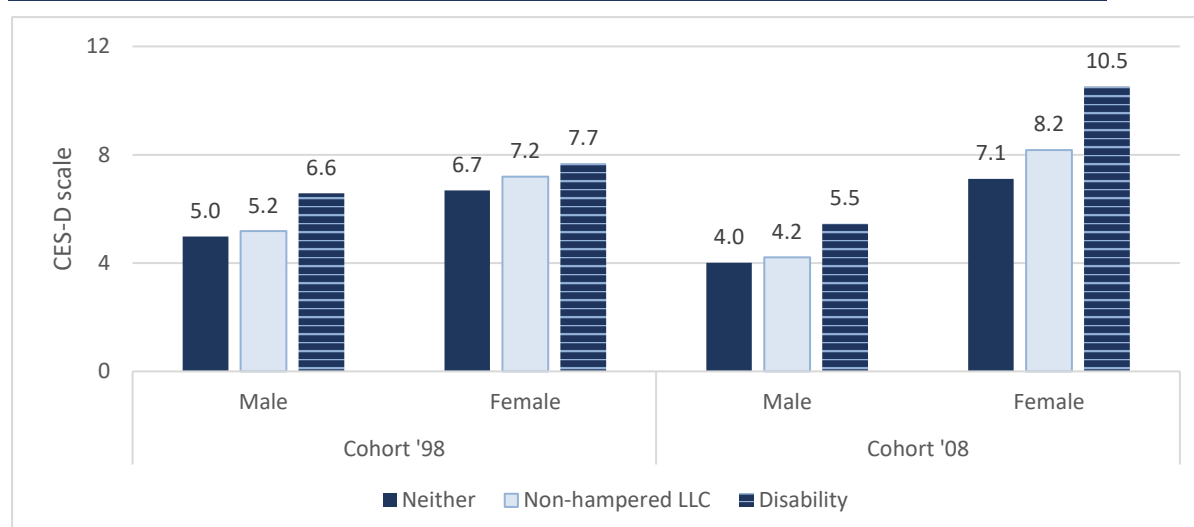
For reasons of statistical disclosure, the measure of physical health has been recoded into two groups: very healthy, no problems; and at least some problems.⁸ Figure 2.6 shows that the prevalence of health problems declines between cohorts, from 39 to 28 per cent. For both cohorts, health problems are more prevalent among those who have an LLC (but are not hampered) and, more markedly, those with a disability. Thus, the gap in health status increases between those with a disability and others over time. However, it is also worth noting that a very significant proportion of those who are hampered by a disability (37 per cent for Cohort '98 and 45 per cent for Cohort '08) are described as being 'very healthy, no problems'.

⁸ This combines the categories 'healthy, but a few minor problems', 'sometimes quite ill' and 'almost always unwell'. The latter categories become too small to report when broken down by disability status.

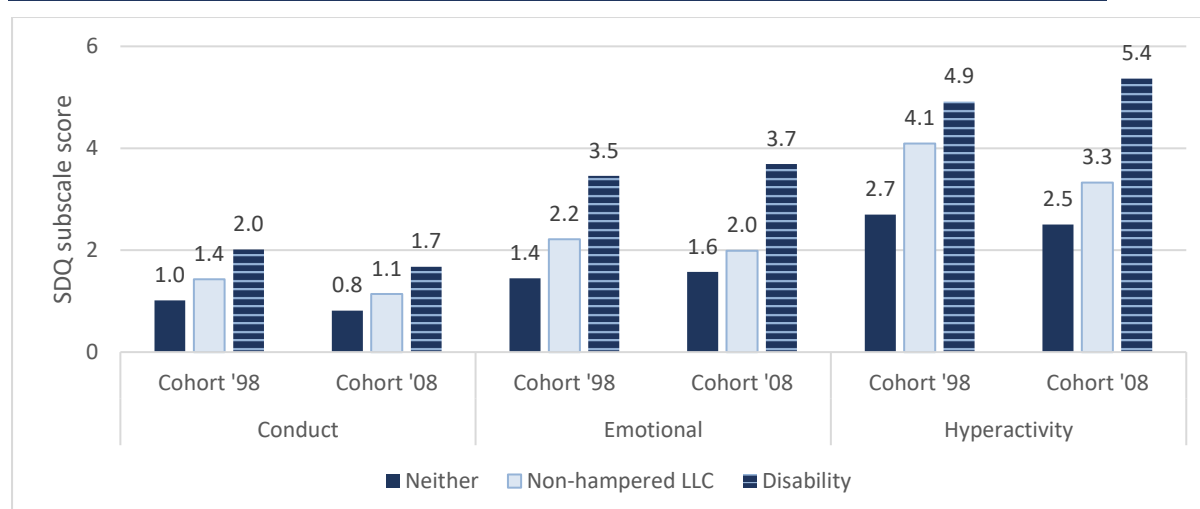
FIGURE 2.6 PERCENTAGE HAVING AT LEAST SOME HEALTH PROBLEMS BY DISABILITY STATUS AND COHORT AT AGE 13

Source: GUI Cohorts '98 and '08.

For both cohorts, the Center for Epidemiological Studies-Depression (CES-D) measure of depressive symptoms was administered to 13-year-olds on a self-complete basis. There is no significant difference in average score between cohorts, but this obscures important differences by gender: scores increased for girls over time but decreased for boys. For this reason, Figure 2.7 breaks down average depression scores by disability status, gender and cohort. For males and females in both cohorts, the highest average depression levels are found among those with a disability. Among girls, depression levels are higher among the non-hampered LLC group than among those with neither an LLC nor a disability. However, this difference is less marked for boys, for whom the main distinction is between those with a disability and all others. Depression scores increased over time for all groups of girls but this growth is very marked for girls with a disability.

FIGURE 2.7 MEAN DEPRESSION SCORE (CES-D) BY GENDER, DISABILITY STATUS AND COHORT

Source: GUI Cohorts '98 and '08.

FIGURE 2.8 MEAN LEVEL OF SOCIO-EMOTIONAL DIFFICULTIES (SDQ SUBSCALES) BY DISABILITY STATUS AND COHORT: BOYS

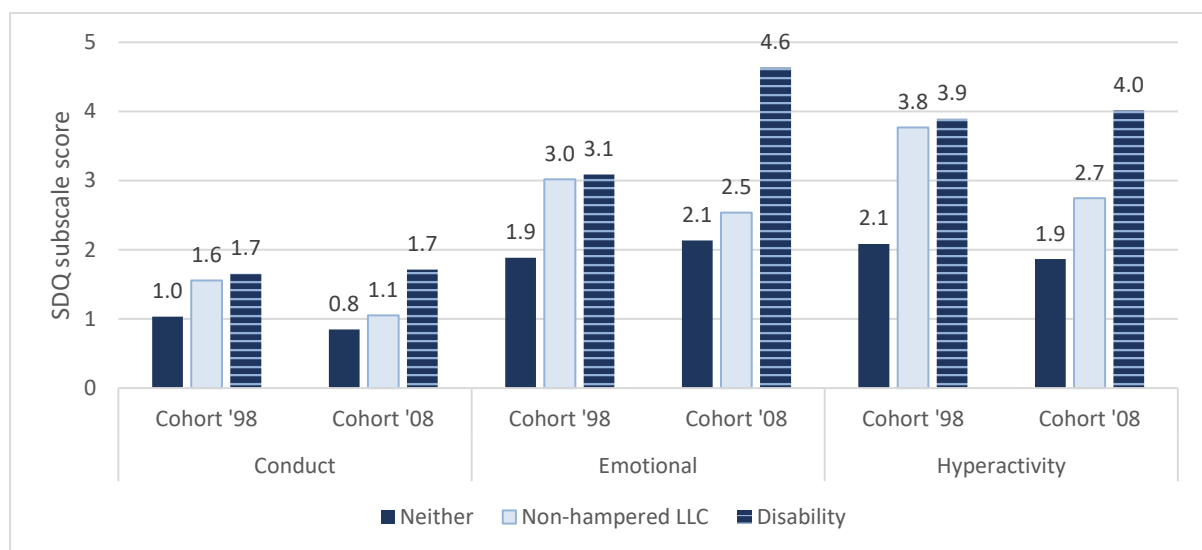
Source: GUI Cohorts '98 and '08.

Figures 2.8 and 2.9 show the average level of socio-emotional difficulties, measured using the Strengths and Difficulties Questionnaire (SDQ), for boys and girls respectively, broken down by disability status.⁹ Boys in the non-hampered LLC group have higher levels of conduct, emotional and hyperactivity problems than those with neither an LLC nor a disability, while levels are even higher for those with a disability. The pattern of change over time varies between different types

⁹ The SDQ is a widely used measure of socio-emotional difficulties internationally. It includes five subscales – four capturing difficulties around conduct, hyperactivity, emotional and peer relations, and one capturing a positive element of prosocial behaviour. The total difficulties score includes the four subscales capturing difficulties.

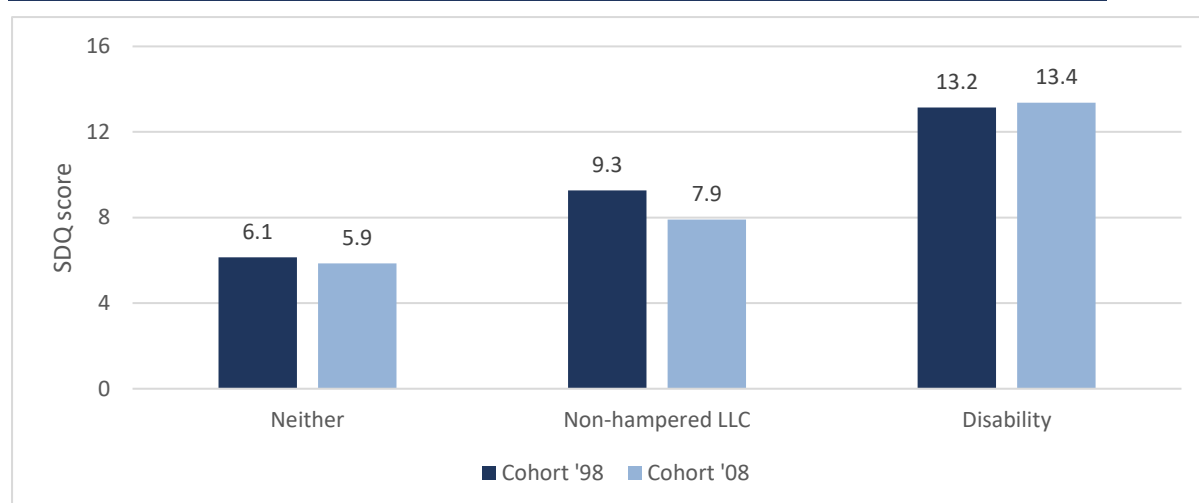
of socio-emotional difficulties. The reported level of conduct difficulties declines between cohorts for all groups of boys, including those with a disability. For emotional difficulties, levels increase slightly for those with a disability and for those without an LLC/disability, but decline slightly for those in the non-hampered LLC group. In contrast, hyperactivity levels increase markedly for those with a disability while they decline for both the non-hampered LLC and the non-LLC/disability groups. As a result, the gap in emotional and hyperactivity difficulties between boys with a disability and others increases over time, while those with an LLC but who are not hampered come to more closely resemble the non-LLC/disability group.

FIGURE 2.9 MEAN LEVEL OF SOCIO-EMOTIONAL DIFFICULTIES (SDQ SUBSCALES) BY DISABILITY STATUS AND COHORT: GIRLS

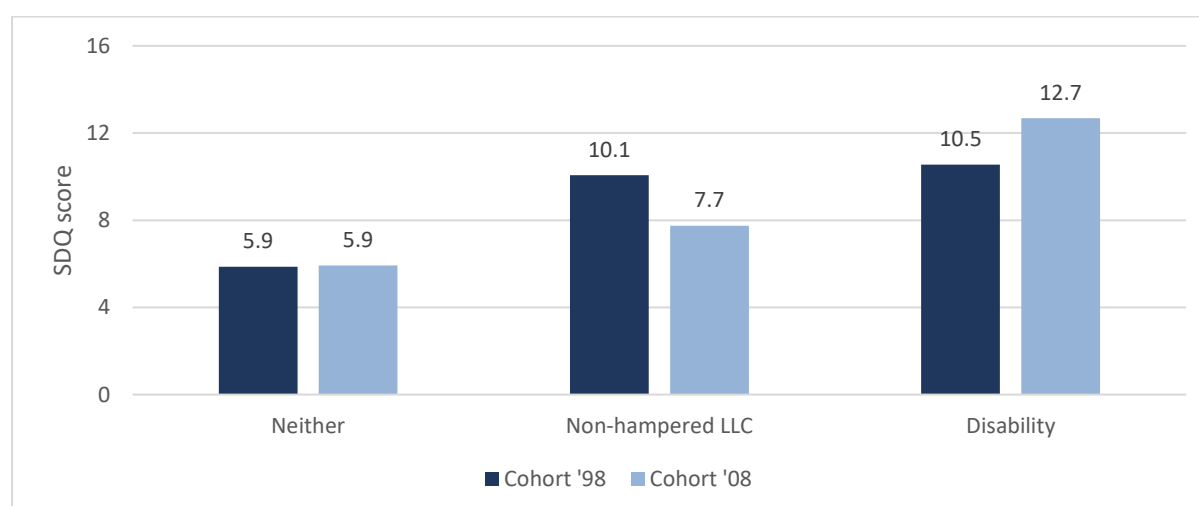


Source: GUI Cohorts '98 and '08.

For girls, socio-emotional difficulties are greater among those with a disability but the differences between the non-hampered LLC and disability groups are marginal for all three subscales for Cohort '98. Conduct difficulties decline among the 'neither' and non-hampered LLC groups, but remain stable for those with a disability. Emotional difficulties increase very markedly for girls with a disability, while levels decline for those in the non-hampered LLC group and increase slightly for the 'neither' group. Hyperactivity levels decline for the non-hampered LLC and 'neither' groups but increase very slightly for those with a disability. As for boys, the gap between the non-hampered LLC group and those without an LLC/disability seems to narrow over time, meaning a greater difference in difficulty levels between the disability group and all others.

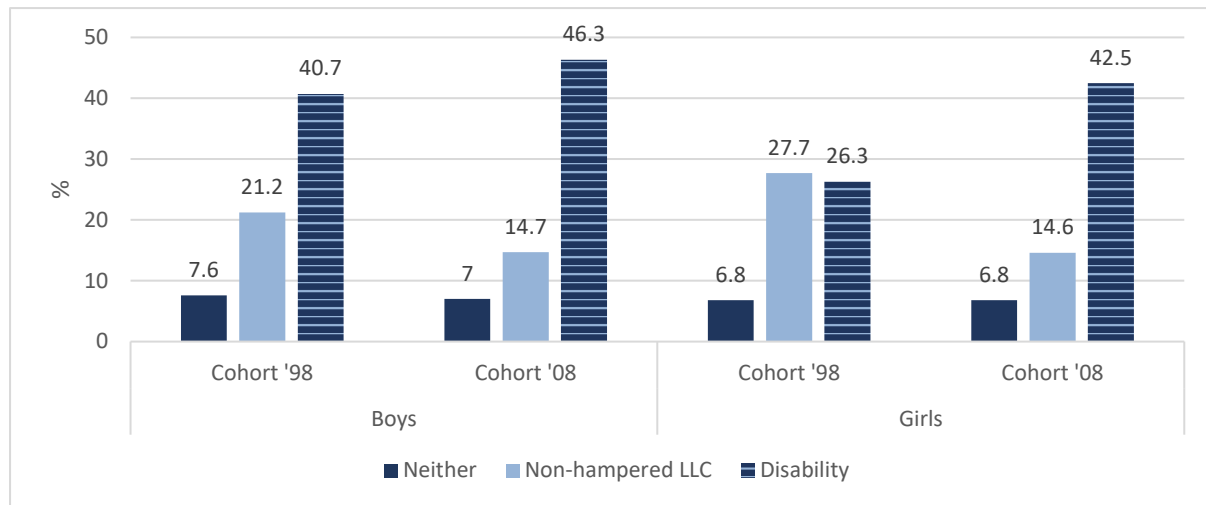
FIGURE 2.10 MEAN LEVEL OF SOCIO-EMOTIONAL DIFFICULTIES (SDQ TOTAL DIFFICULTIES) BY DISABILITY STATUS AND COHORT: BOYS

Source: GUI Cohorts '98 and '08.

FIGURE 2.11 MEAN LEVEL OF SOCIO-EMOTIONAL DIFFICULTIES (SDQ TOTAL DIFFICULTIES) BY DISABILITY STATUS AND COHORT: GIRLS

Source: GUI Cohorts '98 and '08.

These three subscales, along with a measure of peer difficulties, can be summed to give an overall measure of total socio-emotional difficulties (Figures 2.10 and 2.11). Among both boys and girls, there is a marked decline in difficulties among those with an LLC but who are not hampered by it. For those without an LLC/disability, difficulties decline slightly for boys but remain stable for girls. Among those with a disability, difficulties increase for both genders but do so much more markedly for girls.

FIGURE 2.12 PERCENTAGE WITH A 'PROBLEMATIC' OR 'BORDERLINE' SDQ SCORE (14 OR MORE) BY GENDER, DISABILITY STATUS AND COHORT

Source: GUI Cohorts '98 and '08.

The analyses so far have looked at average SDQ scores, but it is possible to separate out the group that have 'problematic' or 'borderline' scores (14 or more) to distinguish those for whom socio-emotional difficulties are likely to be more consequential. High scores are most common among those with a disability and lowest among those without an LLC/disability, with over four in ten of those with a disability having high scores among Cohort '08 (Figure 2.12). The pattern is slightly different for girls in Cohort '98, where problematic SDQ levels were similarly high among those in the non-hampered LLC and the disability groups. As with average SDQ scores, being in the high-score group becomes less prevalent over time for the non-hampered LLC group, for both girls and boys. In contrast, the chances of being in the high-score group increases for both girls and boys with a disability, with a very large increase evident for girls.

2.4 CONCLUSIONS

This chapter has looked at the profile of young people by disability status and the extent of overlap between having an LLC or disability and key dimensions of health and wellbeing. There has been a shift in the gender profile of those who have an LLC or disability, with this being more common among boys than girls in Cohort '98; a decade later, for Cohort '08, no marked gender differences are evident. While it is difficult to determine what accounts for this shift, the evidence on socio-emotional difficulties suggests that the pattern relates to an increase in emotional difficulties among girls. This trend is consistent with the disproportionate increase in socio-emotional difficulties previously found among girls in several countries,

including Ireland (Daly, 2022; Nilsen et al., 2024; Potrebny et al., 2024; Dooley et al., 2019).¹⁰

There has been a growth in disability prevalence among all social groups over the decade studied. However, disability prevalence varies by some family background factors, with higher rates of disability found among young people from lone-parent families and those living in rented accommodation. Lower rates of disability or LLC are found among those from migrant-origin families. International studies have highlighted differences in the prevalence of disability among migrant-origin children, depending on the country studied (Morinaga et al., 2021; Gao et al., 2022) or by type of condition within the same country (Hansen et al., 2023). There are no consistent explanations for any such differences, which may be due to cross-cultural differences in the identification of disabilities or to less insider knowledge among migrant-origin parents in how to access supports or diagnoses. Evidence on migrant-origin adults in Ireland indicates that they are less likely to access GP or consultant services (Barlow et al., 2021), a pattern that may also influence diagnosis of conditions for children and young people.

Among Cohort '08, just over half of those with a disability and one-third of those in the non-hampered LLC group are reported to have at least some health problems, a lower level than was the case for Cohort '98. In contrast, high levels of socio-emotional difficulties and, for girls, average depression scores have increased over time among those with a disability. We had hypothesised that increased levels of LLC/disability might reflect greater identification of conditions rather than an increase in underlying need. It does appear that both sets of factors are at play. For both boys and girls, the non-hampered LLC group seems to become more like the non-LLC/disability group over time in terms of mental health and wellbeing, supporting the identification hypothesis. However, there is a greater gap in mental health and wellbeing between those with a disability and others than previously. Furthermore, problematic levels of socio-emotional difficulties become more prevalent among those with a disability, especially among girls, suggesting increased need among this group. The trend in type of socio-emotional difficulties differs by gender: girls with a disability are more likely to have emotional difficulties and depressive symptoms than previously, while boys with a disability are more likely to have hyperactivity issues.

¹⁰ There has been little consensus on the factors potentially driving this pattern, with some studies pointing to school-related stress (Högberg et al., 2020) and others highlighting the effects of social media (Kelly et al., 2018; Haidt, 2024).

CHAPTER 3

Outcomes among young people with disabilities

3.1 INTRODUCTION

This chapter looks at selected outcomes among 13-year-olds and the extent to which these vary by disability status and between cohorts. The outcomes have been selected to capture key dimensions of experiences, including the quality of relationships with parents and peers, involvement in out-of-school sports and attitudes to school. These outcomes were also chosen on the basis of differences found in earlier analyses between those with a long-lasting condition (LLC) and others (Smyth, 2024). As these earlier analyses found no differences for those with an LLC in relation to screen time and involvement in cultural activities, these outcomes are not explored further here. As discussed in Chapters 1 and 2, if identification of those with an LLC or disability has increased over time (without any shift in the underlying prevalence), then we would expect that the differences between those with an LLC/disability and others would reduce between cohorts.

3.2 RELATIONSHIPS WITH PARENTS

Table 3.1 presents the results of models looking at four aspects of the parent–child relationship (measured at age 13): mother-reported conflict with the young person, father-reported conflict with the young person, whether the 13-year-old reports getting on very well with their mother and how responsive they find their mother. All of these analyses control for other factors that potentially influence relationship quality, including gender, parental education, social class, experience of financial strain, migrant status, family size and structure, urban/rural location, living in rented accommodation (private or social) and school year group.

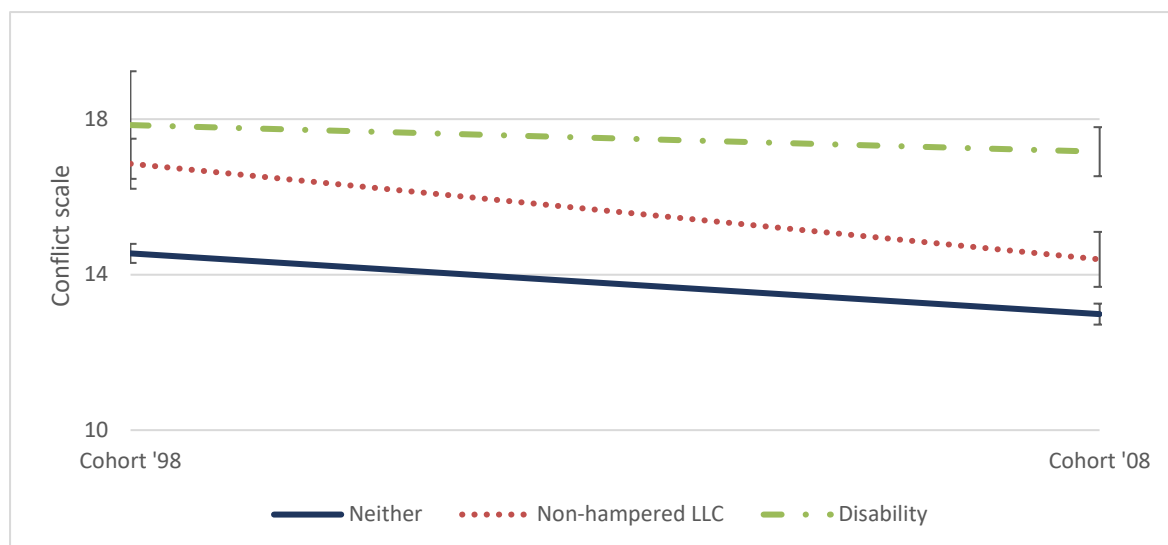
Both mothers and fathers report significantly greater levels of conflict if their child has an LLC or disability, with the highest levels found among those with a disability (Table 3.1). We are interested not only in this overall difference but also in whether the scale of the effect changed between cohorts. Interaction terms (the interaction between cohort and disability status) can be difficult to interpret from a table. Therefore, Figures 3.1 and 3.2 present the predicted patterns based on the model results for mother–child and father–child conflict, respectively. The figures show a decline in conflict levels between cohorts for all three groups. However, the decline is not statistically significant for young people with a disability (with overlapping confidence intervals around estimates). Moreover, those who have an LLC but are not hampered by it more closely resemble those without an LLC/disability among the younger cohort.

TABLE 3.1 REGRESSION MODELS OF PARENT–CHILD RELATIONSHIPS AT AGE 13 AND CHANGES OVER TIME

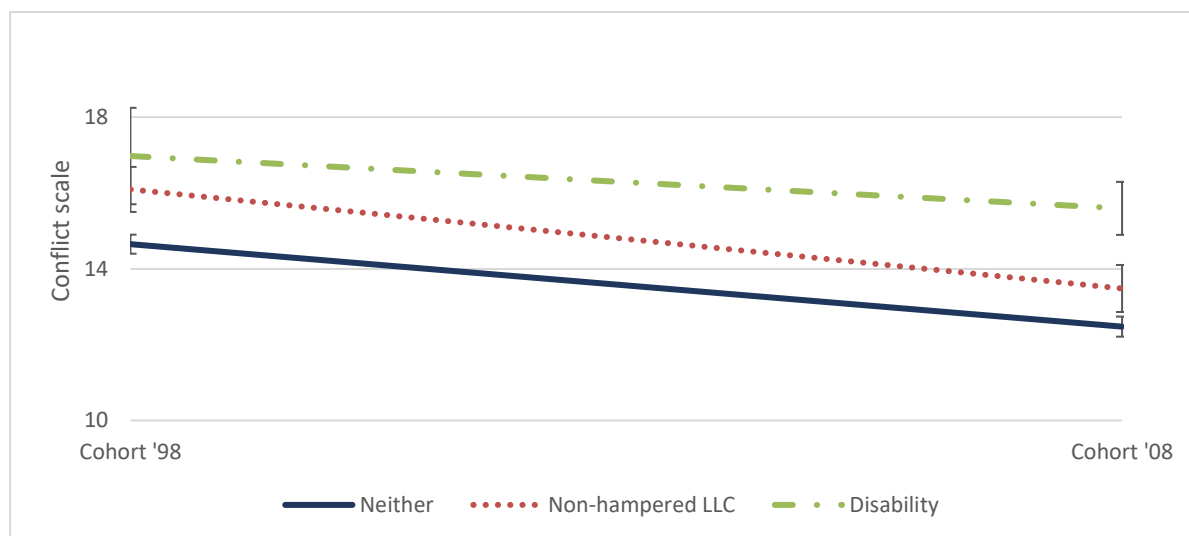
	Mother–child conflict		Father–child conflict		Gets on very well with mother (YP) (Odds ratios)		Maternal responsiveness (YP)	
	Model 1	Model 2	Model 1	Model 2	Model 1	Model 2	Model 1	Model 2
Constant	12.993	12.997	13.394	13.418	7.780	7.745	20.817	20.840
Cohort '08	-1.613***	-1.563***	-2.167***	-2.175***	0.921	0.947	4.714***	4.729***
Disability status:								
Not hampered by LLC								
Disability (hampered by LLC)	1.883***	2.306***	1.239***	1.444***	0.814±	0.856	-0.435**	-0.440*
(Ref. Neither)	4.035***	3.301***	2.943***	2.325***	0.752*	0.766	-0.429	-0.323
Disability*Cohort '08:								
Not hampered		-0.897		-0.437		0.860		0.018
Hampered		0.878		0.795		0.960		-0.173
Adjusted R²/Nagelkerke R²	0.068	0.069	0.063	0.063	0.018	0.018	0.272	0.273
N	12,046	12,046	9,170	9,170	8,709	8,709	8,468	8,468

Source: GUI Cohorts '98 and '08.

Notes: Models for mother–child conflict, father–child conflict and maternal responsiveness are OLS regression models. The model for the child getting on very well with their mother is a logistic regression model. All of the models control for gender, parental education, social class, experience of financial strain, migrant status, family size and structure, urban/rural location, living in rented accommodation (private or social) and school year group. *** significant at the $p < .001$ level, ** $p < .01$, * $p < .05$, ± $p < .10$. YP = Young person's report.

FIGURE 3.1 PREDICTED MOTHER–CHILD CONFLICT BY DISABILITY STATUS ACROSS COHORTS

Source: Derived from Model 2 in Table 3.1.

FIGURE 3.2 PREDICTED FATHER–CHILD CONFLICT BY DISABILITY STATUS ACROSS COHORTS

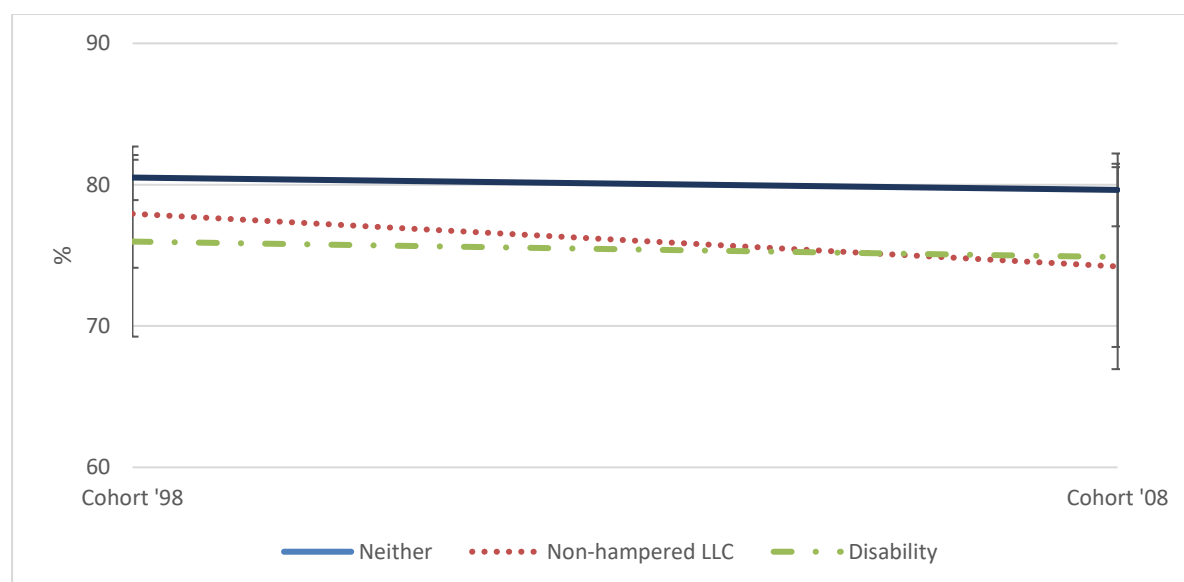
Source: Derived from Model 2 in Table 3.1.

In contrast to parental reports, there is much less variation by disability status in young people's reports of the quality of their relationship with their mother. Those with a disability are less likely to say they get on very well with their mother,¹¹ while those who have an LLC but are not hampered by it report lower levels of maternal responsiveness. The proportion who report getting on very well with their mother

¹¹ Odds ratios are reported in Table 3.1 because average marginal effects (AMEs) cannot be calculated for interaction terms. Using AMEs for Model 1, the difference between those with a disability and those with no LLC/disability is around five percentage points, controlling for other factors.

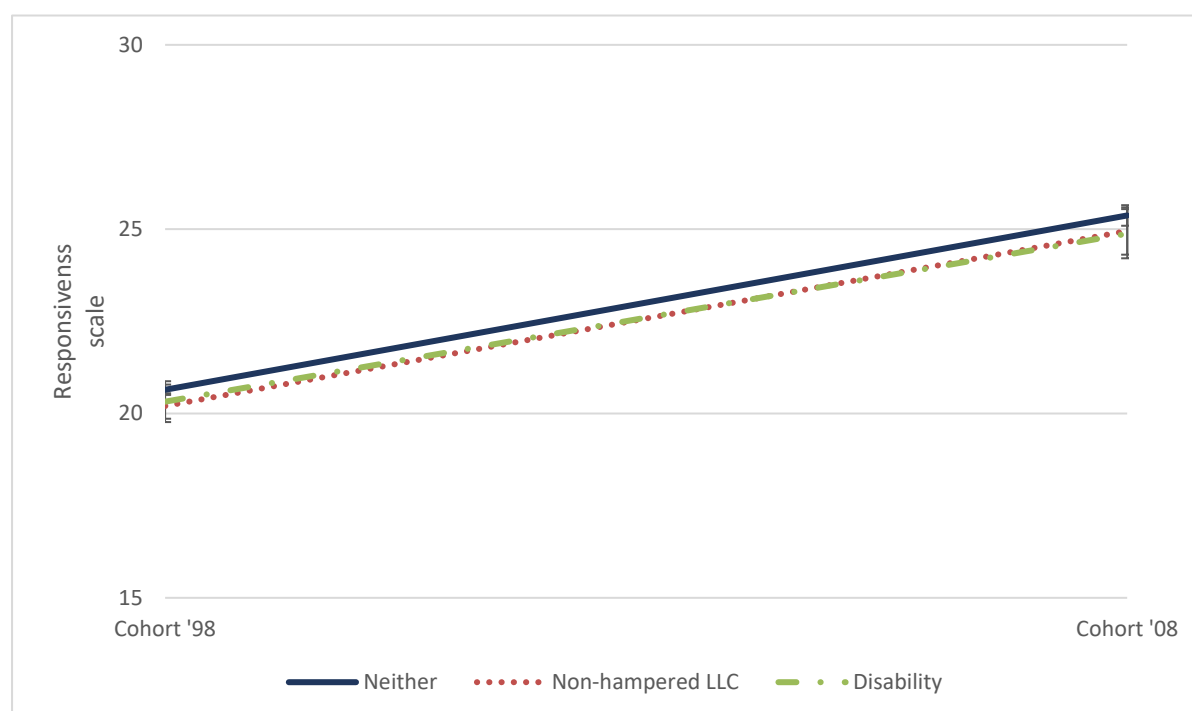
is also relatively stable over time, with no significant shift between cohorts, as evidenced by the overlapping confidence intervals in Figure 3.3. In contrast, there is an improvement over time in perceived maternal responsiveness that applies to all groups regardless of disability status (Figure 3.4).

FIGURE 3.3 PREDICTED PERCENTAGE OF YOUNG PEOPLE WHO GET ON VERY WELL WITH THEIR MOTHER BY DISABILITY STATUS ACROSS COHORTS



Source: Derived from Model 2 in Table 3.1.

FIGURE 3.4 PREDICTED MATERNAL RESPONSIVENESS BY DISABILITY STATUS ACROSS COHORTS



Source: Derived from Model 2 in Table 3.1.

3.3 RELATIONSHIPS WITH PEERS

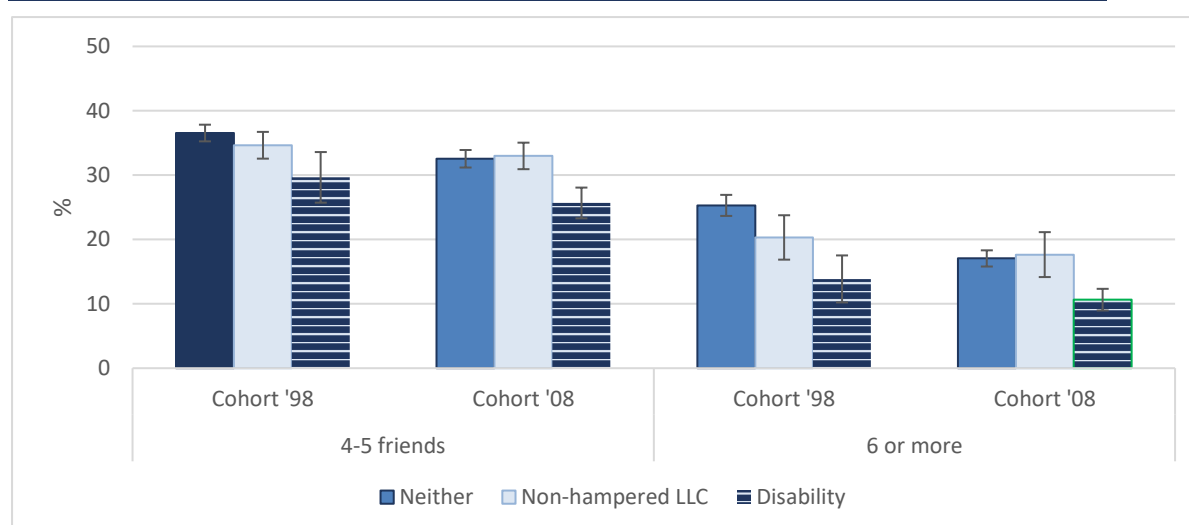
In terms of the size of the friendship group, those with an LLC but are not hampered by it have fewer close friends (but this is only significant at the $p<.10$ level), and those with a disability have substantially fewer friends than their peers (Table 3.2). The number of close friends reported by young people reduces significantly between cohorts. Figure 3.5 shows that the pattern of change varies by disability status, with those in the non-hampered LLC group more closely resembling those with no LLC/disability among the younger cohort and a clearer gap in peer group size emerging between those with a disability and all others.

TABLE 3.2 ORDERED LOGIT MODEL OF NUMBER OF CLOSE FRIENDS AT AGE 13 AND CHANGES OVER TIME (ODDS RATIOS)

	Model 1	Model 2
Threshold:		
1	-4.778***	-4.802***
2–3	-2.962***	-2.986***
4–5	-0.435***	-0.458***
6 or more	1.129***	1.108***
Cohort '08	0.646***	0.607***
Disability status:		
Not hampered by LLC	0.880±	0.753*
Disability (hampered by LLC)	0.545***	0.476***
(Ref. Neither)		
Disability*Cohort '08:		
Not hampered		1.384*
Hampered		1.219
Pseudo R²	0.019	0.019
N	11,640	11,640

Source: GUI Cohorts '98 and '08.

Notes: All of the models control for gender, parental education, social class, experience of financial strain, migrant status, family size and structure, urban/rural location and living in rented accommodation (private or social). *** significant at the $p<.001$ level, ** $p<.01$, * $p<.05$, ± $p<.10$.

FIGURE 3.5 PREDICTED PERCENTAGE OF YOUNG PEOPLE WITH FOUR/FIVE OR SIX OR MORE CLOSE FRIENDS BY DISABILITY STATUS ACROSS COHORTS

Source: Derived from Model 2 in Table 3.2.

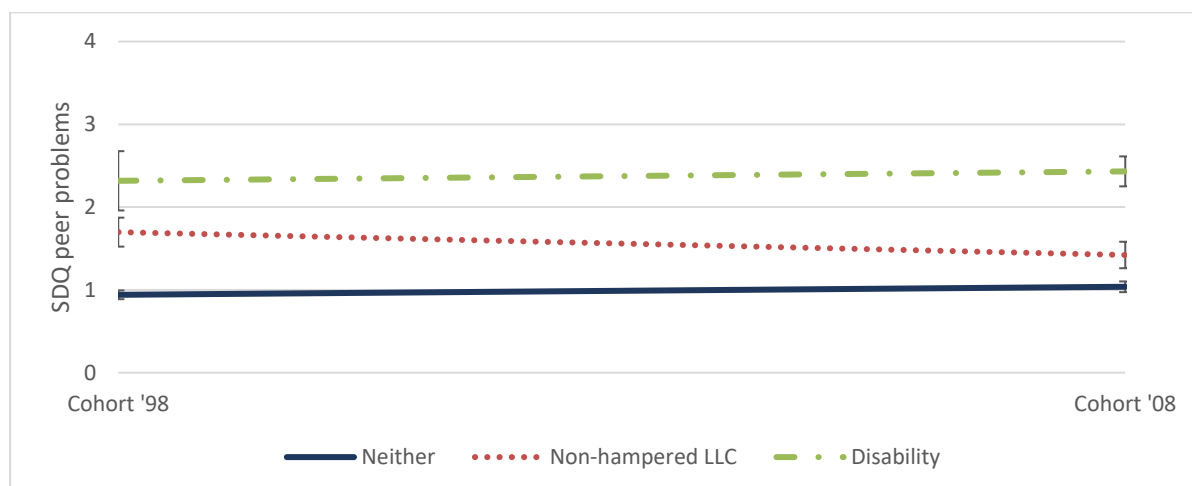
TABLE 3.3 OLS REGRESSION MODEL OF PEER PROBLEMS (SDQ SUBSCALE) AT AGE 13 AND CHANGES OVER TIME

	Model 1	Model 2
Constant	0.910	0.893
Cohort '08	0.045	0.097*
Disability status:		
Not hampered by LLC		
Disability (hampered by LLC)	0.582***	0.757***
(Ref. Neither)	1.409***	1.377***
Disability*Cohort '08:		
Not hampered		-0.374**
Hampered		0.017
Adjusted R²	0.122	0.124
N	12,054	12,054

Source: GUI Cohorts '98 and '08.

Notes: All of the models control for gender, parental education, social class, experience of financial strain, migrant status, family size and structure, urban/rural location and living in rented accommodation (private or social). *** significant at the $p < .001$ level, ** $p < .01$, * $p < .05$, $\pm p < .10$.

There are substantial differences in relation to difficulties interacting with peers, as reported by mothers, by disability status (Table 3.3). Much greater peer problems (measured using the SDQ subscale) are found among those with a disability. Looking at change over time (Figure 3.6), those in the non-hampered LLC group come to more closely resemble those with no LLC/disability among the younger cohort; in other words, there is a decline in peer problems among those who have an LLC but are not hampered by it, while differences between those with a disability and all others are generally stable.

FIGURE 3.6 PREDICTED SDQ PEER PROBLEMS BY DISABILITY STATUS ACROSS COHORTS

Source: Derived from Model 2 in Table 3.3.

3.4 INVOLVEMENT IN SPORTS

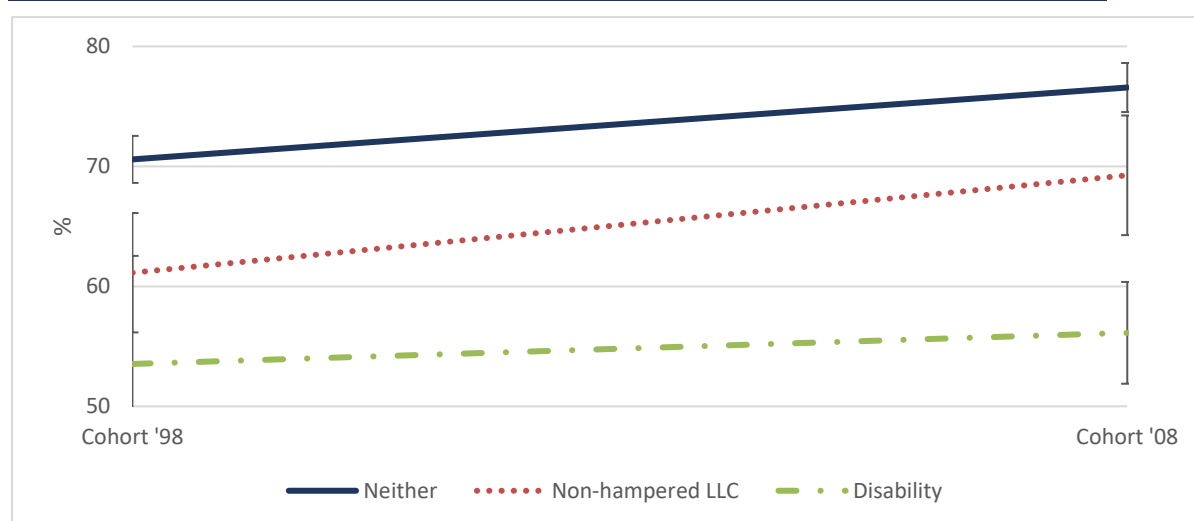
Rates of weekly involvement in organised sports are found to be significantly lower among those with an LLC, whether or not they are hampered by it (Table 3.4). These are sizeable gaps: compared to those without an LLC or disability, levels of involvement are 8 per cent lower for those in the non-hampered LLC group and 19 per cent lower for those with a disability. Involvement levels increase for all groups over time (Figure 3.7). However, the rate of increase is much less for those with a disability, resulting in the non-hampered LLC group more closely resembling the non-LLC/disability group among the younger cohort.

TABLE 3.4 LOGISTIC REGRESSION MODEL OF DAILY INVOLVEMENT IN ORGANISED SPORTS AND CHANGES OVER TIME (ODDS RATIOS)

	Model 1	Model 2
Constant	2.165	2.146
Cohort '08	1.343***	1.362***
Disability:		
Not hampered (LLC)	0.671***	0.656***
Disability (hampered by LLC)	0.409***	0.480***
Disability status:		
Not hampered by LLC		1.051
Hampered		0.815
(Ref. Neither)		
Pseudo R²	0.079	0.079
N	11,782	11,782

Source: GUI Cohorts '98 and '08.

Notes: All of the models control for gender, parental education, social class, experience of financial strain, migrant status, family size and structure, urban/rural location and living in rented accommodation (private or social). *** significant at the $p < .001$ level, ** $p < .01$, * $p < .05$, ± $p < .10$.

FIGURE 3.7 PREDICTED PERCENTAGE OF YOUNG PEOPLE INVOLVED IN ORGANISED SPORTS AT LEAST WEEKLY BY DISABILITY STATUS ACROSS COHORTS

Source: Derived from Model 2 in Table 3.4.

3.5 ATTITUDES TO SCHOOL

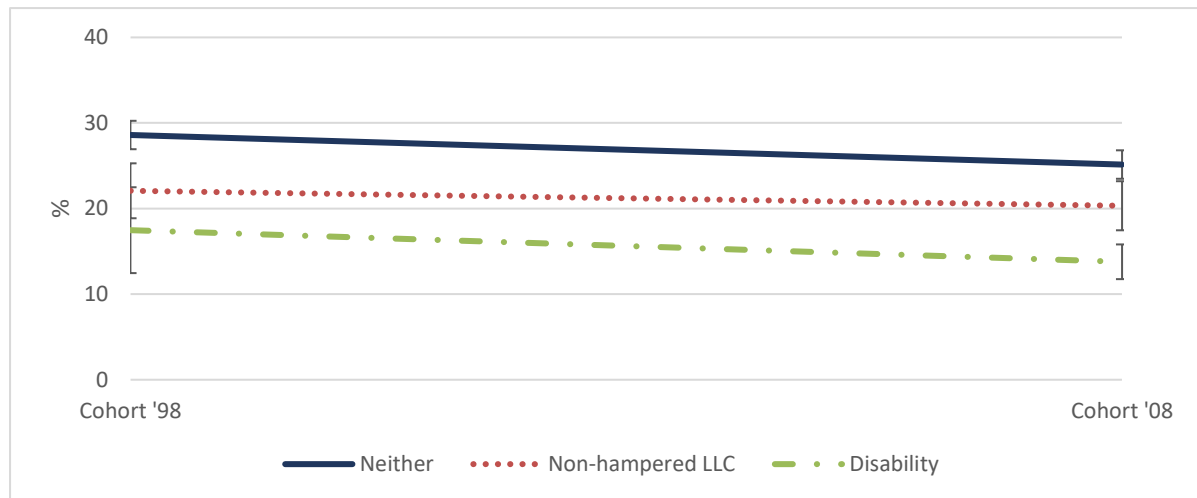
The 13-year-olds were asked how they felt about school in general, with higher values indicating more negative attitudes. Attitudes to school are more negative among those who have an LLC but are not hampered by it and even more negative among those with a disability (Table 3.5). Attitudes become more negative between cohorts (see the cohort coefficient in Table 3.5). Figure 3.8 shows what the predicted patterns look like for the group who like school very much. Attitudes become less positive for all groups, though the decrease is less for those in the non-hampered LLC group.

TABLE 3.5 ORDINAL LOGIT MODEL OF NEGATIVE ATTITUDES TO SCHOOL AT AGE 13 AND CHANGES OVER TIME (BASE GROUP: LIKE SCHOOL VERY MUCH) (ODDS RATIOS)

	Model 1	Model 2
Cohort '08	1.191**	1.192**
Disability status:		
Not hampered by LLC	1.366***	1.414**
Disability (hampered by LLC) (Ref. Neither)	2.058***	1.891***
Disability*Cohort '08:		
Not hampered		0.931
Hampered		1.111
Pseudo R²	0.024	0.024
N	11,653	11,653

Source: GUI Cohorts '98 and '08.

Notes: All of the models control for gender, parental education, social class, experience of financial strain, migrant status, family size and structure, urban/rural location and living in rented accommodation (private or social). *** significant at the $p < .001$ level, ** $p < .01$, * $p < .05$, $\pm$ $p < .10$.

FIGURE 3.8 PREDICTED PERCENTAGE OF YOUNG PEOPLE WHO LIKE SCHOOL VERY MUCH BY DISABILITY STATUS ACROSS COHORTS

Source: Derived from Model 2 in Table 3.5.

3.6 CONCLUSIONS

This chapter has looked at key outcomes in the domains of relationships with parents and peers, involvement in out-of-school activities and attitudes to school. Clear differences are evident: young people with an LLC or disability have more conflictual relationships with their parents, smaller peer networks, greater difficulties interacting with peers, less involvement in organised sports and more negative attitudes to school compared to their peers. The only dimension where these differences are not as strong relates to a young person's own perspective on their relationship with their mother.

Comparing the two GUI cohorts, some aspects of young people's lives have become more positive over the decade, with less conflict with parents and greater sports involvement, while other aspects have become somewhat more negative, with smaller circles of friends and slightly less positive attitudes to school (Smyth, 2024). Chapters 1 and 2 have shown a significant shift in the size and profile of those with an LLC or disability between cohorts. If this relates to increased identification (without any shift in the underlying prevalence), then we would expect that the differences between those with an LLC/disability and others would reduce between cohorts. For several of these outcomes, a decline in differences between groups is apparent for the group who have an LLC but are not hampered by it, with these young people more closely resembling those without an LLC or disability in the recent cohort. This may relate to increasing identification of LLCs that do not impinge on day-to-day activities. However, it should be noted that other factors, such as more inclusive practice in schools or greater societal awareness of illness and disability, may have also made a difference. In contrast, across most of the outcomes explored, there remains a substantial and growing gap between those with a disability and those without an LLC/disability, indicating no increased inclusion and/or greater severity of need among this group.

CHAPTER 4

Conclusions and implications for policy

4.1 INTRODUCTION

This report draws on analyses of the two cohorts of the *Growing Up in Ireland* (GUI) study to examine trends in the prevalence of disability among 13-year-olds over the decade 2011/2012 to 2021/2022. The study was prompted by previous analyses of GUI data (Smyth, 2022, 2024), which showed a significant increase in the number of 9- and 13-year-olds reported to have a long-lasting condition (LLC) or disability. The analyses distinguish between young people who have an LLC and are hampered, at least to some extent, by that condition (the disability group), those who have an LLC but are not hampered by it (the non-hampered LLC group) and those without an LLC/disability. The report looks at changes over time in the size and composition of these groups, as well as the presence of socio-emotional difficulties and/or depressive symptoms among these groups. Growing numbers of those with an LLC or disability may reflect greater identification of conditions over time and/or greater prevalence. In order to examine these competing explanations, we look at the consequences of having an LLC or disability for a number of adolescent outcomes, including relationships with parents and peers, day-to-day activities and attitudes to school.

4.2 THE PREVALENCE OF LONG-LASTING CONDITIONS AND DISABILITY

The prevalence and profile of disability are highly dependent on the definitions and measures used (Hagerman and Houtrow, 2020; Panagi et al., 2022). Estimation is made all the more challenging by changes in the measures used in GUI between cohorts and between survey waves within cohorts. These changes reflect a broader shift in the understanding of disability in society, with a move away from a focus on diagnostic categories towards a social model of disability that emphasises functioning in particular contexts or environments (see, for example, Fovet, 2023). Based on mother reports, the proportion of 13-year-olds with an LLC (whether or not they are hampered by it) has increased from 24 per cent for Cohort '98 to 36 per cent for Cohort '08. As well as being asked about the presence of conditions, mothers were asked about whether their child had received a diagnosis for that condition. The proportion of the total cohort who had received at least one diagnosis increased from 16 per cent for Cohort '98 to 31 per cent for Cohort '08. The group with a disability (that is, an LLC that hampers their activities at least to some extent) grew from 6 per cent for Cohort '98 to 23 per cent for Cohort '08. A growth in the prevalence of disability is also evident in Census figures, though Census estimates tend to be lower than those based on GUI data (see also Banks and McCoy, 2011; Whelan et al., 2021).

There has been a growth in the prevalence of disability and LLCs among all social groups over the period 2011/2012 to 2021/2022. There has been a shift in the gender composition of these groups, with having an LLC or disability being more common among boys than girls in Cohort '98 but no marked gender differences evident a decade later. While it is difficult to determine what accounts for this shift on the basis of available data, the evidence on socio-emotional difficulties suggests that the pattern relates to an increase in emotional difficulties among girls. A disproportionate increase in depressive symptoms and anxiety among girls has been found in earlier Irish research (Dooley et al., 2019), as well as in research from a number of other Western countries (Durbeej et al., 2019; Nilsen et al., 2024).

Changes in the classification of types of conditions, alongside small sample sizes for several groups, make it challenging to look at which particular conditions are driving the overall increase. Among those with an LLC who are not hampered by the condition, there is an increase in both respiratory and behavioural difficulties, the largest groups, over time. The increase is particularly marked for behavioural difficulties, increasing from 1 to 17 per cent between cohorts at age 13. The proportion with an emotional/behavioural disability that hampers their activities has increased from 1.1 per cent of the total cohort in Cohort '98 to 13.5 per cent in Cohort '08. Principals report a corresponding increase in the prevalence of emotional and behavioural difficulties in their school, with over ten per cent of principals now reporting that one-quarter or more of their students have such difficulties.

4.3 DISABILITY, HEALTH AND WELLBEING

Three aspects of health and wellbeing were explored: mother reports of the young person's general health; mother reports of socio-emotional difficulties (measured using the Strengths and Difficulties Questionnaire (SDQ)); and young person reports of depressive symptoms. For both cohorts, health problems are more prevalent among those with an LLC and, more markedly, those with a disability, than among those with neither. However, it is worth noting that around four in ten of those who are hampered by a disability are described as being 'very healthy, no problems'. Problematic levels of socio-emotional difficulties and, for girls, average depression scores are found to have increased over time among those with a disability, indicating no diminution of need among the group. In contrast, the non-hampered LLC group seems to become more like the group with neither an LLC or disability over time in terms of mental health and wellbeing, suggesting that there may be greater identification of LLCs that do not generally hamper the lives of young people.

4.4 DISABILITY AND ADOLESCENT OUTCOMES

The study examines differences by disability status in relationships with parents and peers, involvement in organised sports and attitudes to school. Clear

differences in adolescent outcomes are evident: young people with an LLC or disability have more conflictual relationships with their parents, smaller peer networks, greater difficulties interacting with peers, less involvement in organised sports and more negative attitudes to school compared to their peers. The only outcome analysed where differences are not as strong relates to a young person's own perspective on their relationship with their mother.

Growth in the prevalence of LLCs or disabilities may reflect two processes. The first is an increased identification of conditions as a result of greater awareness among parents, doctors, teachers and other practitioners. The second is a greater prevalence of certain conditions and/or higher levels of need. The study findings point to both sets of factors being at play. Increased identification should mean that the group with an LLC or disability would become more heterogeneous in profile. This appears to be the case for those with an LLC but who are not hampered by it. They come to more closely resemble the non-LLC/disability group over time in relation to several outcomes, including socio-emotional difficulties. Of course, it may be the case that other factors, such as more inclusive practice in schools or greater societal awareness of illness/disability, may have also helped to reduce the extent to which young people are hampered by their condition. In contrast, there remains a substantial and growing gap between those with a disability and those without an LLC/disability, indicating that growing prevalence reflects the presence of conditions that impact on young people's day-to-day lives.

4.5 IMPLICATIONS FOR POLICY

The study findings point to a significant growth over time in the proportion of 13-year-olds reported to have an LLC or disability, with an increase evident across all social groups but a greater increase for girls than boys. The most commonly reported difficulties among those with a disability now relate to physical impairment and difficulties learning, remembering or concentrating, conditions that have different implications for the resources and supports required to enhance the inclusion of these young people.

The evidence points to a greater identification of long-lasting illnesses or conditions that do not hamper young people's day-to-day lives, with this group coming to more closely resemble their peers without an LLC/disability in terms of their socio-emotional wellbeing and mental health, relationships, activities and school engagement. In contrast, there are clear levels of need, including increasing need in some domains, among young people with a disability in terms of their socio-emotional wellbeing as well as their social and educational outcomes.

The study findings have implications for a range of policy areas, including disability, health, education, family support and recreation, and suggest the importance of a joined-up approach in promoting the full inclusion of young people with a disability. While there has been a good deal of policy development in relation to

inclusive practice, the findings point to a number of areas for further development. There has been considerable policy development around Supporting Parents, the new national model for parenting support services (DCEDIY, 2022). The findings suggest the need to target supports towards families of children and teenagers with a disability, given the higher levels of parent–child conflict evident in these contexts. Using data on Cohort '98 at nine years of age, Banks et al. (2018) highlighted how attending a mainstream school is not sufficient to ensure social integration, with fewer friends among those with a special educational need (SEN), particularly those with emotional–behavioural problems. They suggested the need for a greater emphasis on school-based efforts to promote integration. Fourteen years later, young people with a disability still have fewer friends and are more likely to have difficulties interacting with peers (as reported by their mothers). Further research could usefully explore which groups of young people experience greater difficulties and examine whether these processes reflect social distance or experience of more negative behaviour like bullying. School and classroom climate are crucial too in promoting greater school engagement among young people with a disability (see McCoy and Banks, 2012), given the more negative attitudes to school shown here and less positive attitudes to core school subjects shown in Smyth (2024). The findings on the low levels of involvement in sport among young people with a disability suggest the importance of inclusive practice in out-of-school as well as in-school provision and the need to address attitudinal barriers and lack of choice of suitable activities (see Sport Ireland, 2022). This is all the more important given the role that sport and physical exercise can play in promoting socio-emotional wellbeing as well as physical health.

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