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MEASURING CHILDHOOD DISABILITY AND AIM PROGRAMME PROVISION IN IRELAND

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ABBREVIATIONS

ADHD	Attention deficit hyperactivity disorder
ADL	Activities of daily living
AIM	Access and Inclusion Model
AMF	Anonymised microfile
ASD	Autism spectrum disorder
ASFR	Age-specific fertility rate
CCF	Community Childcare Subvention
CSO	Central Statistics Office
DCEDIY	Department of Children, Equality, Disability, Integration and Youth
ECCE	Early Childhood Care and Education scheme
ELSA	The English Longitudinal Study of Ageing
GLD	General learning disability
GUI	<i>Growing Up in Ireland</i> study
HRB	Health Research Board
IADL	Instrumental activities of daily living
ICF	International Classification of Functioning Disability and Health
NASS	National Ability Supports System
NIDD	National Intellectual Disability Database
NPSDD	National Physical and Sensory Disability Database
NDA	National Disability Authority
OECD	Organisation for Economic Co-operation and Development
PCG	Primary caregiver
PIP	Pobal's Programmes Implementation Platform
RMF	Research microdata files
SDQ	Strengths and Difficulties Questionnaire
SEN	Special educational need
TEC	Training and Employment Childcare programme
TFR	Total fertility rate
TILDA	The Irish Longitudinal Study on Ageing
UN	United Nations
WHO	World Health Organization
WHODAS	WHO Disability Assessment Schedule

EXECUTIVE SUMMARY

The social inclusion of children with disabilities is crucial to their development and wellbeing. It is critical therefore that children with disabilities have equal access to early years provision and that adequate supports are put in place to facilitate this. Research on the prevalence of childhood disability and the circumstances and characteristics of children with disabilities is crucial for public policy development regarding appropriate and timely service provision. In order to plan for future educational support needs for children with disabilities and to help inform policy in the area, this report examines various aspects of childhood disability, with a particular focus on the 3-5 year old pre-school population.

Measurement of the prevalence of disability among children is a difficult undertaking. The conceptualisation of disability is multifaceted and has evolved over time. Different datasets typically adopt different classifications of disabilities. The research in this study focuses on the self-reported information in the Census of Population, 2011 and 2016, and the data from the *Growing Up in Ireland* (GUI) study. We also examine data from the Access and Inclusion Model (AIM) programme, which represents the main initiative in Ireland designed to facilitate children with disabilities to access mainstream early years education for pre-school children. Ensuring children with disabilities can fully participate in early years education is important; it is well documented that early education provision is a means of counteracting social exclusion (European Commission, 2013) and leads to happier children (Disability Federation of Ireland, 2017).

Based on the CSO Census data, 4.25 per cent of children aged 3-5 years had a disability in 2011, with the figure rising to 4.54 per cent in 2016. The disability categories in the Census data are not mutually exclusive. In terms of the identifiable disabilities, intellectual disabilities were the most dominant among 3-5 year olds in 2011 at 2.06 per cent, followed by physical disabilities at 1.71 per cent. The incidence of 3-5 year olds with blindness/deafness and psychological/emotional disabilities was approximately 0.54 per cent and 0.59 per cent respectively in 2011. However, in both periods the single largest category of disability among children aged 3-5 was the 'other' category; this grouping incorporates rather broad responses related to (i) other disabilities including chronic illness and (ii) difficulties in participating in other activities. We found that this 'other' category overlaps most frequently with disabilities related to basic mobility and those measures that assess difficulties in carrying out daily activities, such as dressing and leaving the house.

We examined the incidence of childhood disability by county and found that during both time periods, the incidence of childhood disability was consistently higher than expected (given the population size) in Offaly and Limerick and consistently

lower than expected in Clare and Leitrim. By this, we mean the distribution of childhood disability in Ireland does not appear to be geographically neutral. The disability rate increased between 2011 and 2016 in all but seven counties: Donegal, Galway, Kildare, Leitrim, Roscommon, Sligo and Westmeath.

Childhood disability appears more prevalent in data from the the GUI study, which measures disability primarily on the basis of teacher assessments of 5 year olds, than it does in estimates from the Central Statistics Office (CSO). The GUI estimate of childhood disability overall is 8.82 per cent compared to the total childhood disability rate estimate from the Census (2016) of 4.54 per cent. The categories examining blindness, deafness and difficulties with physical activities closely align across the two estimates.¹ The GUI estimates for intellectual disability, difficulty with learning, remembering or concentrating, and psychological or emotional conditions are higher than the Census estimates.

Participation in the AIM programme is voluntary and relies on an application being made to the service, so we would never expect to see 100 per cent of children with disabilities utilising the programme.² Moreover, there is no clear sense of what the most appropriate rate of utilisation is for such a programme. Not all children with a disability will need support to participate fully in early education. In 2016, for most counties, the number of children availing of AIM equated to between 10 and 30 per cent of the estimated number of children with disabilities aged 3-5, based on the CSO data. In 2019, the situation appears to have changed radically, with between 45 per cent and 80 per cent of the estimated children with disabilities receiving some level of support from AIM. This may point to a rapid expansion of both provision or take-up, or a combination of the two, between the launch of the programme in 2016 and 2019. The nature of the programme means that some supports, such as staff training, would take a period of time to implement.

Demographic projections indicate that the number of children with disabilities is likely to decline over time. As AIM is demand-led it is difficult to envisage how this will impact the reach of the programme in the future, which will depend not only on the number of children with disabilities but also on the complexity of these disabilities and the support required. However, if we assume that the number of children with disabilities declines, in line with demographic projections, with no change to complexity and types of disability, then AIM may be able to support more children in the future; in addition, demand for AIM may fall as the number of children needing support declines.

¹ The defined categories for blindness and deafness from the Census of Population include vision impairment, blindness, hearing impairment and deafness.

² An application for AIM is made by the pre-school provider in partnership with the parent and completed parental consent is required to process the application.

Finally, we use the GUI survey to look more closely at difficulties faced by children. The GUI analysis reports much higher levels of difficulty among pre-school children; however, it is noted that broad definitions of disability/difficulty are used, which include sight/hearing difficulties, speech difficulties as well as emotional and behavioural difficulties. The GUI analysis identifies that difficulties at this age can emerge and recede over time and that most children have only one difficulty, with the recorded occurrence of multiple disabilities/difficulties being uncommon.

CHAPTER 1

Introduction

1.1 BACKGROUND

International evidence has demonstrated that access to pre-school programmes positively impacts subsequent learning in language, literacy and mathematics (Weiland and Yoshikawa, 2013). Ireland, in line with most other developed countries, has extended early learning and care substantially over recent times. Currently, all children in Ireland can benefit from two years free preschool education (for 15 hours per week throughout the school year of 38 weeks). However, as in all other educational contexts, it is important that children with disabilities have equal access to early learning and care provision and that adequate supports are put in place to facilitate this. To help plan future educational support needs for children with disabilities, it is useful for policymakers to get some assessment of both the current incidence of childhood disability and potential future trends.

The objective of this research is to contribute to this policy debate by addressing the following questions:

1. What is the current incidence of childhood disability among 3-5 year old children in Ireland?
2. To what extent does the incidence of childhood disability vary at county level?
3. What is the current level of pre-school supports for children with disabilities, provided by the Access and Inclusion Model (AIM) programme, and how are these evolving over time?
4. How does the level of pre-school support coordinate with the estimated levels of need at a county level?
5. How is the incidence and distribution of childhood disability likely to change over time?
6. How will future provision need to evolve to meet future demand?
7. To what extent do children classified as having a disability have multiple disabilities? What are the most common combinations of disabilities?
8. Are there any environmental factors correlated with multiple disabilities?

Measurement of the prevalence of disability among children is a difficult task. The conceptualisation of disability is multifaceted and has evolved over time. Different datasets typically adopt different classifications of disabilities. Even in instances where common categories are used, it is possible to get widely varying estimates of the incidences, depending on the process by which disability is identified. The measurement of the disability rate is affected by how the data are collected and/or

on the qualifying conditions for a particular type of support. Approaches to identifying individuals with disabilities within data collection frameworks range from self-reporting (in the case of children, reporting by a primary caregiver (PCG)), to diagnostic-based approaches involving the opinions of caregivers and/or the use of observational assessments.

Data on the prevalence of childhood disability and the circumstances and characteristics of children with disabilities is crucial for public policy development and providing appropriate and timely service provision.

The remainder of this chapter presents a review of the literature, methodology and the relevant data sources. Chapter 2 explores disability rates for children within the early years education sector (aged 3-5 years). Chapter 3 examines the provision of AIM supports designed to enable children with disabilities to access the Early Childhood Care and Education (ECCE) programme. Chapter 4 examines the evolution of need at a regional level in the short to medium term. Chapter 5 uses the *Growing Up in Ireland* (GUI) dataset to estimate the rate of disabilities and additional needs among young children in Ireland and shows how these rates differ under different definitions. This chapter also examines the prevalence of multiple difficulties among children at age 3 and age 5. Finally, Chapter 6 presents a summary and considers a number of policy implications arising from the research. Detailed tables exploring childhood disability rates and AIM provision are presented throughout the report and in the appendix.

1.2 LITERATURE REVIEW

1.2.1 Measuring disability internationally

Disability is an evolving concept over time. Once thought of as a purely medical problem for an individual, disability is now deemed a social construct. Individuals are not limited by their impairments but by the society in which they reside (Watson and Vehmas, 2012), which is not set up to be accessible by all. However, this means disability is subjective from person to person and this does not transfer well into defining disability or measuring disability. Furthermore, definitions can change depending on what exactly is being measured and the purpose for which this measurement takes place. It is widely recognised that neither the medical nor the social model do enough to deal with the complexity of disability (Anastasiou and Kauffman, 2013).

The World Health Organization (WHO) developed a model that combines both the health and the environmental context to measure disability. The International Classification of Functioning, Disability and Health (ICF) is now widely used as one method of measuring disability. However, being context-dependent, it does not provide one specific definition for disability:

[T]he ICF does not dictate who is 'normal' and who is 'disabled'. Using the ICF a person or a group can be identified as having 'disability' within each setting or use. What are universal and standard are the underlying concept and the dimensions of functions; the thresholds may change according to the purpose of the use case. (WHO, 2013)

As the ICF cannot be explicitly used as a disability measure, the WHO went on to develop the WHO Disability Assessment Schedule (WHODAS). WHODAS was designed to be an internationally comparable and easily administered measure of disability. It has six domains: cognition; mobility; self-care; getting along; life activities (e.g. work, school leisure or domestic duties); and participation.

The UN Convention on the Right of Persons with Disabilities defines disability as:

[T]hose who have long-term physical, mental, intellectual or sensory impairment which, in interaction with various barriers, many hinder their full and effective participation in society on an equal basis with others. (Eurostat, 2019)

As is the case in most countries, current legislation in Ireland uses an ICF, or biopsychosocial, approach in defining disability. The Disability Act 2005 uses the following definition:

'[D]isability', in relation to a person, means a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State by reason of an enduring physical, sensory, mental health or intellectual impairment.

The Employment Equality Acts (1998-2015) cover a range of impairments in defining disability, as well as past disability: 'to include disability which exists at present, or which previously existed but no longer exists, or which may exist in the future or which is imputed to a person'. By contrast, in gauging whether or not a respondent has any illness, infirmity or impairment, the Census (CSO, 2016) asks if they have 'one or more of the following long-lasting conditions or difficulties:

- blindness or a serious vision impairment
- deafness of a serious hearing impairment
- a difficulty with basic physical activities such as walking, climbing stairs, reaching, lifting, or carrying
- an intellectual disability
- a difficulty with learning, remembering, or concentrating
- a psychological or emotional condition
- a difficulty with pain, breathing, or any other chronic illness or condition.'

For those who answer in the affirmative, this question is followed with one on how their condition affects daily activities, asking, 'Do you have any difficulty in doing any of the following activities?'

- Dressing, bathing, or getting around inside the home;
- Going outside the home alone to shop or visit a doctor's surgery;
- Working at a job or business or attending school or college;
- Participating in other activities, for example leisure or using transport'.

While these definitions overlap significantly, differences do exist, which makes gathering information on the number of people living with disabilities in Ireland quite complex.

The World Bank, in a review of disability prevalence measures, which pointed to the lack of robust comparable measures, put forward that no one measure is sufficient and that at least two should be used: one based on moderate functional limitations and another one for those limitations deemed to be more severe (Mont, 2007). The case for utilising various measures is also put forth by Palmer and Harley (2012), who argue that definitions should be chosen based on the research questions. The difficulties associated with measuring disability, and in particular special educational needs (SEN), have been discussed in an Irish context by Desforges and Lindsay (2010).

1.2.2 Measuring childhood disability

The social inclusion of children with disabilities is crucial to their development and wellbeing (Odom et al., 2011; Odom, 2000; Johnsson and Kossykh, 2008). In order to meet the needs of children and their families, policymakers need accurate measures of SEN. However, measuring disabilities and additional support needs among children often leads to discrepancies and inconsistencies. While some sources rely on data collected by PCGs (through surveys or the Census), others suggest that data from teachers, or screening processes, could provide data with fewer false positives (Stuckey and Albitron, 2020). Authors often differ in the overall measures they use.

Childhood disability is not as well documented as it is for adults, and this is the case across all developed countries. Like disability in adulthood, this is attributed to, among other things, the difficulty in pinning down a definition, differences in purposes of data collection and the fact that disability can often be dynamic with movements into and out of disability. While statistics often exist, they differ between sources and therefore may lack reliability. The National Disability Authority (NDA) puts this down to the lack of a 'sharp' definition for disability. This is further complicated by the fact that childhood disability is unlikely to be reported by the child but rather by a proxy – their PCGs (usually the child's parent). The will to report one's child as having a disability will vary depending on how the

definition being used matches with the PCGs' own definition of disability, how they view the difficulties the child experiences (a possibility of under- or over-stating) and if they are concerned about the inferences arising from labelling a child as disabled (Blackburn et al., 2010).

The Blackburn et al. (2010) study provides a comprehensive look at childhood disability in the UK for those aged 0 to 18 years. Using the UK's legal definition at the time – that outlined in the Disability Discrimination Act (1995 and 2005) – they find a prevalence rate of 7.3 per cent.³ However, this rate varies considerably by gender, with 5.8 per cent of girls considered disabled compared to 8.8 per cent of boys. Blackburn et al. (2010) also found that disability prevalence among children increases with age, with a significant difference between those 4 years and under and those aged 5 to 11 (3.7 per cent and 8.2 per cent, respectively). The study found that memory, concentration and learning difficulties are the most common problems among children with disabilities.

Stein and Silver (2002) examined the prevalence of childhood disability and chronic illness in the US, using four different definitions. They found significant variation between the definitions tested, all of which were complex and built upon a series of questions from four different surveys to characterise individuals.

Other studies use Census information to consider disability rates under different definitions (Newacheck and Halfon, 2000; Newacheck et al., 1984; Cappa et al., 2015), while others like GUI (Gallagher et al., 2020; Banks and McCoy, 2011) have used more focused household surveys. Some researchers have used specific samples of children from existing programmes and services, as well as systematic screening, as means of assessing the full range of needs found in these populations (Sinclair, 1993; Stuckey and Albitron, 2020). Sinclair (1993) argued that different methods of collecting and defining disability will lead to different rates, and that certain types of gatekeeping may lead to underestimations of disability and difficulty.

Definitions of disability have also changed over time, and there has been a shift in research and policy away from a medical model of disability based on the physical and emotional conditions of the individual, diagnosis and medical gatekeeping and towards a biopsychosocial model in which disability is understood in terms of how the individual interacts with the physical and social environment (Watson and Nolan, 2011). These changes can lead to differences in how needs are measured and in the prevalence and distribution of disability rates.

³ According to the Disability Discrimination Act, a person is considered disabled if they have any 'physical or mental impairment which has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities'.

Newacheck and Halfon (2000) found that changes in the rates of childhood disability over time can be influenced by alterations to question-wording, changes in access to services, greater societal awareness and changing diagnostic practices. Cappa et al. (2015) made a similar claim in their study, which used data from Brazil, arguing that changes in definitions and measurement create major challenges in producing reliable and comparable statistics. In the 2000 Census of the Brazilian population, the disability rate (measured via a set of questions based on activity limitations) was recorded at 15 per cent across all age groups. However, the rate jumped to 24 per cent in the 2010 Census, in which respondents were asked whether they had permanent difficulties with seeing, hearing or mobility, or if they experienced any intellectual difficulties that interfered or limited their abilities to carry out daily activities. On the basis of these findings, Cappa et al. (2015) have warned that conceptual and methodological differences can drastically affect disability statistics, especially when it comes to reporting on children's disability types.

What disability estimates have researchers found in Ireland and what definitions have these researchers used? Gallagher et al. (2020) showed a range of disability rates, depending on the definition. According to them, roughly 17 per cent of 13-year-old children report a diagnosed developmental disability, and that half of this group do not receive adequate support in school. Using the PCG survey from the GUI '98 cohort at age 13, they focus on the following disability and difficulty measures: a physical disability (including a visual and/or a hearing impairment); a specific learning disability (7%); autism spectrum disorder (2%); an emotional or behavioural disorder; and a speech or language difficulty.

Banks and McCoy (2011) used the GUI '98 cohort at 9 years to estimate the prevalence of SEN among children in Ireland according to the definition used in the EPSEN Act. They also undertook a systematic comparison of estimates from different data sources. They reported that the 2006 Census found that 3 per cent of 0–18 year olds had a disability, which compares to 11 per cent in the National Disability Survey (2008) and 17.7 per cent in the National Council for Special Education Implementation Report (2006). Banks and McCoy's broadest definition using data from PCGs and teachers identified a prevalence rate of 25 per cent of 9 year olds. They started with a teacher-defined SEN measure, which includes physical disability, speech impairment, learning disability, and emotional or behavioural problems. Using teacher reports alone, 14 per cent of children are reported as having SEN. When PCGs' reports of disabilities and difficulties are added, the prevalence of SEN rises to 20 per cent. The PCGs' definition includes learning difficulties, communication or coordination disorders, slow progress, speech difficulties, chronic physical or mental health problems, and illnesses and disabilities that hamper daily life. When a measure of teacher-reported socio-emotional difficulties is added (being in the top decile of the Strengths and Difficulties Questionnaire (SDQ) score), the estimate rises to 25 per cent.

Other researchers have suggested that disability types may cluster together into distinct groups. In the US, Sinclair (1993) examined the clinical profile of children in the Head Start programme, which was designed to assist children with SEN for health and socioeconomic reasons. The UCLA Head Start evaluation team considered seven diagnostic measures to consider clusters of disability and difficulty: physical or orthopaedic difficulty; health impairment; specific learning disability; speech impairment; serious emotional difficulty; mental difficulty; and sensory impairment. Each category contained subscales and the authors identified four clusters, three containing overlapping difficulties and a fourth residual category for children who did not belong in any of the other three clusters. The first cluster was made up of children with high rates of social and emotional problems. The second cluster contained children educational problems linked to difficulty with speech and language. The third cluster included children with serious developmental or medical difficulties.

In Ireland, Gallagher et al. (2020) found that multiple or overlapping disabilities are uncommon in the GUI at age 13. Just 4 per cent of children have two or more difficulties and 13 per cent have one disability or difficulty at age 13. Overlapping difficulties are uncommon among this sample and this set of defined disabilities.

In general, there are several challenges in identifying disabilities and special education need among children. As Nowatchek and Halfon (2000), Nowatchek et al. (1984) and Cappa et al. (2015) have shown, subtle changes in how questions are asked can lead to differences in rates. A second challenge lies in how such data are collected and the primary source. Nowatchek and Halfon (2000) highlighted that awareness is important when collecting data from households and PCGs, but identification of an issue can often rely on teacher evaluations. McCoy et al. (2016) argued that the use of teacher surveys to identify emotional or behavioural disabilities may result in an over-representation of certain groups of children, suggesting that relying on teachers alone could skew results. Elsewhere, Stuckey and Albitron (2020) have shown that overidentification of children in need of intervention is common among single screening tests designed to capture such students.

1.2.3 Determinants of childhood disability rates

Research on the determinants of childhood disability is lacking, in part because of the lack of data sources. However, it has been found that economic characteristics pertinent to children are drivers of childhood disability rates. Poverty has been found to be a risk factor for childhood disability while simultaneously childhood disability increases the chances of living in poverty (Boat and Wu, 2015).⁴ Poverty also has an effect on lone parenthood and educational attainment, both of which have been shown to increase the likelihood of a child being classed as disabled

⁴ For a discussion on how poverty causes disability, please see Lustig and Strauser (2007).

(Blackburn et al., 2010). In the US, children who live in poverty are also more likely to have chronic health conditions, more severe conditions and to receive poorer healthcare (Boat and Wu, 2015). In the same jurisdiction, Houtrow et al. (2014) found that children living in poverty have the highest rates of disability, at a rate of 102.6 cases per 1,000 (2010 to 2011), compared to 62.9 cases per 1,000 of those who came from families with the highest level of family income. Again in the US, Brooks-Gunn and Duncan (1997) found that children living in poverty are 1.3 times more likely to have a learning disability or developmental delay than their counterparts living in households above the poverty threshold. The same research study also found that children from poorer homes are more likely to have emotional or behavioural difficulties and worse self-reported physical health.

In another US study, Houtrow et al. (2014) identified an increase in disability rates over time in more socially advantaged households, which is evidence of the dynamic nature of disability and the reporting of the same. They also found that the characteristics of children with disabilities has changed over time and that disability due to physical conditions decreased in the decade preceding their research study (-11.8%) while the number of children with disability due to mental health conditions or neurodevelopmental conditions increased by more than one-fifth (20.9%). Houtrow et al. argued that there are many reasons behind these changes in the prevalence of disability types, which may include improvements in diagnosing conditions, particularly for neurodevelopmental conditions, an increase in the age women are having children and increased provision of services to support children with disability which require a formal diagnosis.

1.2.4 Determinants of adult disability rates

There is extensive international research literature on the determinants of disability rates among adult populations, but most of such studies consider benefit reciprocity rates rather than the prevalence of disability. This is predominately due to the complex nature of defining, and therefore, measuring disability. The international literature finds that disability benefit rates, at least in the case of adults, have a strong inverse relationship to the strength of the local labour market (Bound and Burkhauser, 1999; Autor and Duggan, 2003; Burkhauser and Stapleton, 2004; Duggan and Imberman, 2009; Benítez-Silva et al., 2010; Beatty and Fothergill, 2002, 2013, 2015; and McVicar, 2013). Health, benefit generosity and benefit eligibility have minor roles to play in determining disability benefit rates.

Studies which examine the determinants of self-reported disability are much harder to find, due to differing definitions and the issues around the self-reporting of disability. Mont (2007) found that a simple self-report of whether the respondent considers themselves disabled yields the lowest prevalence rates because of the negative connotations which can be associated with disability and the stigma attached. When self-reports are used, they usually take the form of either activity-limiting disability or work disability. The term activity-limiting

disability refers to those respondents who respond that they are limited by an illness, infirmity or impairment in their ability to carry out everyday tasks. Work disability refers to respondents reporting that the type or amount of paid work they can do is limited due to an illness, infirmity or impairment. Such measures have been used in large-scale representative surveys such as The Irish Longitudinal Study on Ageing (TILDA). There are, however, well-documented issues around the self-reporting of disability. Justification bias is a problem whereby people are more inclined to report being disabled or having poorer health than may be the case in order to justify their behaviour. Justification bias is even more pertinent for work disability (Oguzoglu, 2012) as people use it to rationalise their non-participation in the labour market.

There is a considerable body of literature on social norms and how they can affect self-reporting reliability in surveys. One way around this issue is to use more specific measures of disability, such as doctor diagnoses of certain conditions. Given the strong correlation between age and health/disability, ageing studies can provide good examples of how to measure disability. TILDA, now in its sixth wave, was designed to yield data that can be compared to that from ELSA in England and the HRS in the US. TILDA uses self-reports of activity-limited disability, work disability and overall health but also asks specific questions on conditions with which respondents may have been diagnosed, as well as activities of daily living (ADLs) and detailed questions on the difficulties respondents face when completing daily tasks. The specificity within these questions may lead to more reliable reporting (Baker et al., 2004). However, earlier work by Rodgers and Miller (1997) argued that ADLs were subject to measurement error and this was perhaps the reason behind fluctuating disability prevalence in US longitudinal studies at that time.

Instrumental activities of daily living (IADLs) are also used in some surveys, to ascertain the extent to which respondents experience difficulty with tasks such as managing money or looking after their home (Mont, 2007). ADLs and IADLs may not be particularly relevant for the research at hand, given the considerable differences in typical daily tasks (particularly regarding IADLs) for children versus adults.

The literature on determinants of disability mainly comprises within-country studies, due to the fact that country-level differences in terms of welfare regimes and social norms make between-country studies difficult. The determinants discussed above therefore also explain spatial variation in disability rates.

The literature is somewhat dated when it comes to measuring disability and the determinants of disability but generally there is consensus that measuring disability is complex for the reasons outlined in Section 1.2.1 and that disability rates tend to be determined by the local labour market, with health as a secondary

factor, which reflects the social definition of disability as a social construct rather than individual-level medical problems or physical limitations.

1.3 METHODOLOGY AND DATA SOURCES

Several agencies and government departments in Ireland collect data on disability. However, depending on the definition of disability used, and the main purpose for which the data were originally collected, estimates vary in terms of the number of children. Data sources on people with disabilities include:

- Census of Population (CSO)
- *Growing Up in Ireland* (GUI) study
- Pobal's Programmes Implementation Platform (PIP)
- The Health Research Board's disability databases:
 - National Ability Supports System (NASS)
 - National Intellectual Disability Database (NIDD)
 - National Physical and Sensory Disability Database (NPSDD)
- The National Disability Survey (2008).

As outlined previously, definitions of disability can vary considerably across sources. This study focuses on self-reported information from the Census of Population, 2011 and 2016, and data from the GUI study. The Census of Population takes place every five years and provides detailed information on every person living in Ireland on a particular date. Questions include age, marital status, gender, place of birth, occupation and religion, among other things, and the data play a key role in government planning of public service provision.

Where possible, using the anonymised statistical data, we examine the extent to which multiple disabilities are reported for individual children. The GUI study provides a unique opportunity to combine data from three sets of key informants (children, their PCGs and teachers) to identify within the infant cohort those reporting disabilities at 3 and 5 years. Data collection for the infant cohort started in 2008, involving over 11,000 nine-month-old babies and their families. Follow-up waves were completed when the children were aged 3 years, 5 years and 7-8 years (via a postal questionnaire). Information was collected from PCGs, carers, non-resident PCGs, teachers and principals and all data were anonymised. The lowest level of analysis reported is county level; this is due to data restrictions, considerations around sufficient data quality and confidentiality requirements.

Data from Pobal's PIP platform was also utilised to examine AIM programme provision. PIP was an online administration system, developed in order to streamline the process of implementing early learning care and school-age childcare programmes, as well as the Better Start AIM programme. It was established in 2014, with the aims of reducing levels of documentation associated

with the ECCE, the Community Childcare Subvention (CCS) and Training and Employment Childcare (TEC) programmes, simplifying administration and enabling the programmes to be managed more effectively and efficiently. The PIP system is managed by Pobal on behalf of the Department of Children, Equality, Disability, Integration and Youth (DCEDIY).⁵

Other data sources include the Health Research Board (HRB) disability databases: the National Ability Supports System (NASS), the National Intellectual Disability Database (NIDD) and the National Physical and Sensory Disability Database (NPSDD). We received a selection of data from these data sources for the years spanning 2017 to 2019. However, these data sources were incomplete for the purpose of our study, with some counties not containing any observations for children aged 6 years and below. These are all opt-in databases, so registration is not mandatory and there can be a reluctance among some PCGs to register their child on a 'disability' database. Furthermore, it was suggested that there may also be a lack of engagement with service providers and the HSE as many of the teams involved in returning children's data (early intervention teams) were and remain under-resourced, with long waiting lists; in such circumstances, maintaining the databases has become less of a priority. The National Disability Survey (2008) was also investigated but it is predominately an assessment of the adult population with disabilities and does not include adequate information on the childhood cohort of interest to this study.

⁵ Previously Department of Children and Youth Affairs.

CHAPTER 2

Exploration of early years disability rates

2.1 INTRODUCTION

In this chapter, we begin by analysing data from the Census of Population in 2011 and 2016 to assess the total incidence of disability among children aged 3-5 years in both years. We chose these age cut-off points as they best align with the ages during which children access early learning and care services. We then examine the overall rates according to the type of disability, before considering the spatial distribution of childhood disability by county. In a later section of the chapter, we compare and contrast estimates from the Central Statistics Office (CSO) with those based on data from the *Growing Up in Ireland (GUI)* survey.

2.2 CENSUS OF POPULATION

The Census of Population gathers information on self-reported disability, based on responses to 11 options provided for the question: 'Do you have any of the following long-lasting conditions or disabilities?' Here, we group these 11 responses into the following five categories of disability:

1. Blindness and deafness
 - i. Blindness or a serious vision impairment
 - ii. Deafness or a serious hearing impairment
2. Physical
 - i. A condition that substantially limits one or more basic physical activity
 - ii. Difficulty in dressing, bathing, or getting around inside the home
 - iii. Difficulty in going outside home alone
3. Intellectual
 - i. An intellectual disability
 - ii. Difficulty in learning, remembering, or concentrating
 - iii. Difficulty in working or attending school/college
4. Psychological/emotional
 - i. Psychological or emotional condition
5. Other
 - i. Other disability, including chronic illness
 - ii. Difficulty in participating in other activities.

Some conditions, such as blindness or visual impairment, by their nature will be more accurately reported than others, such as conditions and disabilities that do not fit as succinctly into the options provided by the Census. Autism spectrum disorder (ASD), for example, may be reported as an intellectual disability or as difficulty in learning/attending school, depending on how it manifests in the individual child; it might alternatively be reported under the 'other' category. A better understanding of the prevalence of ASD in children is important as it is becoming increasingly common in many countries (Matson and Kozlowski, 2011).

A 2018 report from the Department of Health found the prevalence of ASD in Ireland to be between 1 and 1.5 per cent, an estimate that was compiled from a variety of data sources. Data from the GUI, discussed in a later section, can be used to provide a better estimate of the prevalence of ASD and learning difficulties.

2.2.1 Childhood disability rates

Based on CSO data, 4.3 per cent of children aged 3-5 years were disabled in 2011, with the figure rising to 4.5 per cent in 2016. This represents an increase of approximately 6.69 per cent in the disability rate among 3-5 year olds over the 2011 to 2016 period (Table 2.1). Table 2.2 provides the rates according to individual disability types. It should be noted that the categories are not mutually exclusive, as respondents can report more than one disability. Thus, the individual disability rates will not sum to the total disability rate in any one year.

TABLE 2.1 DISABILITY RATE OF THOSE AGED 3-5 YEARS, 2011 AND 2016

	Persons with a disability (3-5 years)	Population (3-5 years)	Disability rate (3-5 years)
2011	8,660	203,645	4.25%
2016	9,587	211,315	4.54%
% change	10.70%	3.76%	6.69%

Table 2.2 shows that at 2.1 per cent, intellectual disabilities were the most dominant disability type among 3-5 year olds in 2011, followed by physical disabilities at 1.7 per cent. The incidence of 3-5 year olds with blindness/deafness and psychological/emotional disabilities was approximately 0.5 per cent and 0.6 per cent respectively in 2011. However, in 2011, at 2.8 per cent, the largest single category of disability among children aged 3-5 years were recorded in the 'other' category; this grouping incorporates rather broad responses related to (i) other disabilities including chronic illness and (ii) difficulties in participating in other activities. Table 2.3 shows that while all types of disability overlap with the 'other' category, the dominant relationships are 'a difficulty that limits basic physical activities such as walking, climbing stairs, reaching, lifting, or carrying' and those measures that assess difficulties in carrying out daily activities, that is, 'difficulty dressing, bathing or getting around inside the home', 'difficulty going outside the home alone to shop or visit a doctors surgery' and 'difficulty attending school'.

TABLE 2.2 DISABILITY RATE BY TYPE FOR THOSE AGED 3-5 YEARS, 2011 AND 2016

	Disability rate	Blindness /deafness	Physical	Intellectual	Psychological /emotional	Other	Population
2011	4.25%	0.54%	1.71%	2.06%	0.59%	2.76%	203,645
2016	4.54%	0.64%	2.25%	2.62%	0.99%	2.89%	211,315
% Change in rate	6.69%	19.43%	31.66%	27.15%	68.45%	4.58%	3.77%

The increase of 6.7% in the total disability rate among 3-5 year olds between 2011 and 2016 masks some more substantial variations in the incidences of individual forms of disability. The incidence of psychological, physical and intellectual disabilities all increased by approximately 0.5 percentage points between 2011 and 2016, representing growth rates of 68 per cent, 32 per cent and 27 per cent respectively.

TABLE 2.3 CROSS-TAB OF THOSE RECORDED AS 'OTHER' AND TYPES OF DISABILITY, 2016

	Persons with a disability (3-5 years)	Those reporting as 'other'	Proportion (%)
Blindness or a serious vision impairment	734	316	43%
Deafness or a serious hearing impairment	713	281	39%
A difficulty that limits basic physical activities such as walking, climbing stairs, reaching, lifting, or carrying	1,909	1,522	80%
An intellectual disability	3,055	2,021	66%
A difficulty with learning, remembering, or concentrating	4,093	2,405	59%
A psychological or emotional condition	2,094	1,427	68%
Difficulty dressing, bathing, or getting around inside the home	3,639	2,845	78%
Difficulty going outside the home alone to shop or visit a doctor's surgery	3,731	3,027	81%
Difficulty working at a job, business or attending school or college	2,941	2,569	87%
Persons with a disability	9,587	6,103	64%

2.3 DISTRIBUTION OF DISABILITY BY COUNTY

Table 2.4 shows the incidence of disability for 3-5 year olds by county in both 2011 and 2016. The counties with rates that lie above the national average are highlighted by bold text. In 2011, the incidence of disability ranged from 3.3 per cent in Monaghan to 5.4 per cent in Limerick, with the national average at 4.25 per cent. In 2016, the incidence of disability ranged from 3.6 per cent in Leitrim to 5.8 per cent in Limerick, with the national average at 4.5 per cent.

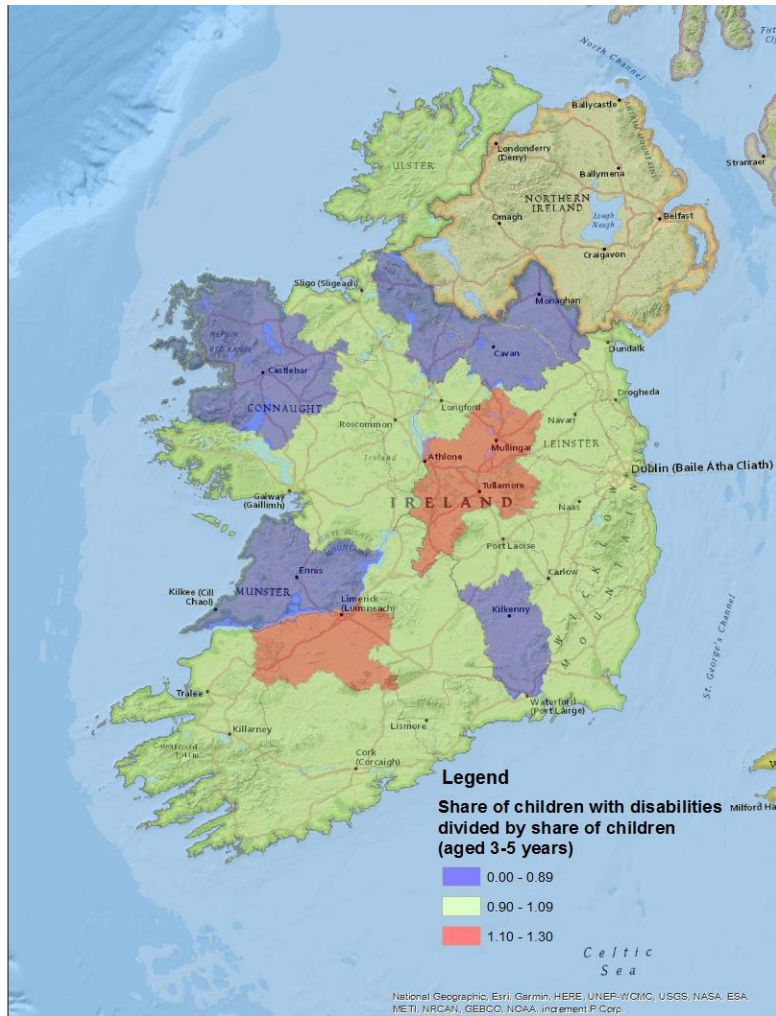
TABLE 2.4 DISABILITY RATES OF THOSE AGED 3-5 YEARS BY COUNTY, 2011 AND 2016

County	2011	2016
Carlow	4.26%	4.95%
Cavan	3.28%	4.16%
Clare	3.77%	4.05%
Cork	4.57%	4.82%
Donegal	4.47%	4.37%
Dublin	4.42%	4.56%
Galway	4.00%	3.76%
Kerry	4.02%	4.49%
Kildare	4.28%	4.18%
Kilkenny	3.47%	4.15%
Laois	4.34%	5.47%
Leitrim	3.65%	3.59%
Limerick	5.40%	5.76%
Longford	3.97%	4.18%
Louth	3.88%	4.56%
Mayo	3.57%	4.11%
Meath	3.86%	4.45%
Monaghan	3.25%	4.07%
Offaly	5.26%	5.81%
Roscommon	3.91%	3.69%
Sligo	4.18%	3.91%
Tipperary	4.31%	4.90%
Waterford	3.84%	4.73%
Westmeath	4.84%	4.75%
Wexford	4.13%	4.13%
Wicklow	3.99%	4.60%
State	4.25%	4.54%

Note: Counties with figures higher than the State average are reported in **bold**.

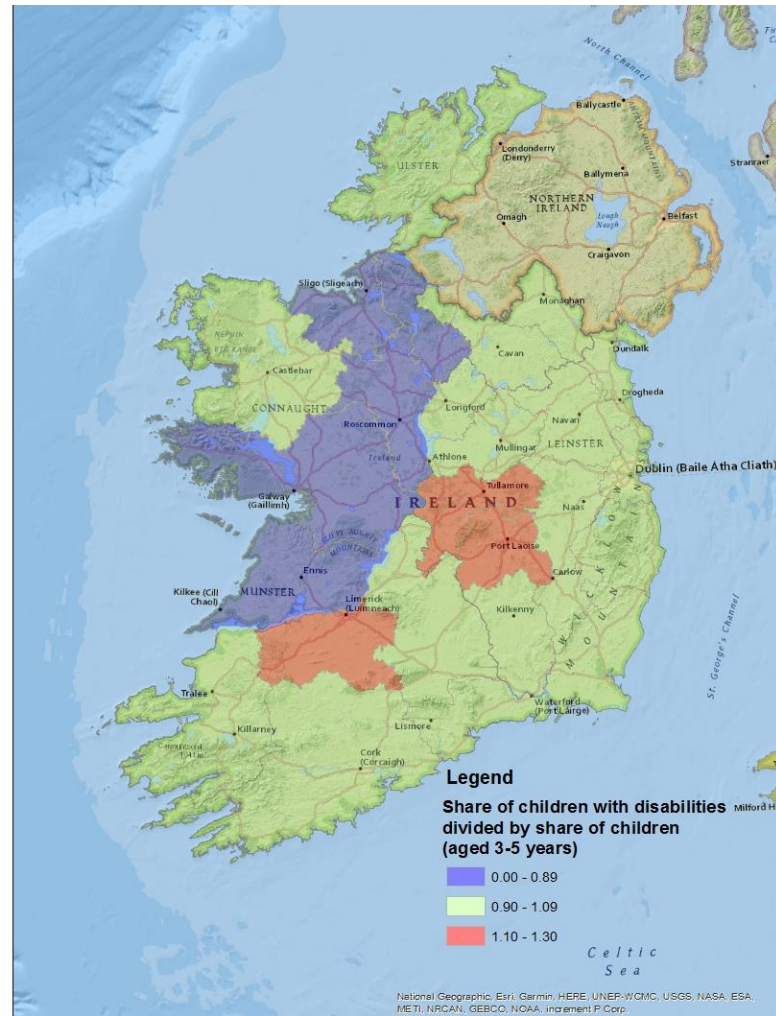
Perhaps a clearer illustration of the county distribution of disability rates is given in Figures 2.1 and 2.2, which plot the ratio of the county-level share of childhood disability to the county-level share of the population for 3-5 year olds. This allows us to examine whether or not the distribution of childhood disability is geographically neutral across Ireland. For instance, if a specific county was to contain three per cent of all children with disabilities in Ireland and account for three per cent of all children in the population, then this will result in a corresponding ratio of one. A ratio of one indicates that the number of children with disabilities in the county aligns with the population of the same age. While the choice of cut-off points may be somewhat arbitrary, we might think of a county with a higher (lower) than expected share of childhood disability as having a ratio above (below) 1.09 (0.9). Taking this approach, counties with levels of childhood disability broadly in line with their population would have ratios in the 0.9 to 1.09 range, or in other words allowing a ten percent range above and below the ratio of one.

FIGURE 2.1 DISABILITY SHARE BY COUNTY, 2011



Source: Census 2011, county-level data.

FIGURE 2.2 DISABILITY SHARE BY COUNTY, 2016



Source: Census 2016, county-level data.

In 2011, childhood disability rates were somewhat higher than expected (based on population figures) in counties Westmeath, Offaly and Limerick, and lower than expected in Monaghan, Cavan, Kilkenny, Mayo, Leitrim and Clare. In 2016, childhood disability rates were somewhat higher than expected based on population in counties Offaly, Laois, and Limerick and lower than expected in Leitrim, Roscommon, Galway, Sligo and Clare. Therefore, over both time periods, the incidence of childhood disability was consistently higher than expected in Offaly and Limerick and consistently lower than expected in Leitrim and Clare.

Tables 2.5 and 2.6 report the county-level incidences for each category of disability in both 2011 and 2016. Any rates that lie above the national average are again highlighted in bold. In 2011, four counties – Donegal, Dublin, Offaly and Westmeath – had higher than average rates for all five disability categories. At the other end of the spectrum, counties Cavan, Clare, Galway, Kilkenny, Leitrim, Louth, Mayo and Monaghan reported incidences below the national average across each of the five categories (Table 2.5). In 2016, the counties that lay above the national average in each disability domain were Cork, Laois, Offaly and Limerick, while Cavan, Clare, Galway, Longford, Mayo and Sligo had below average rates for all disability categories (Table 2.6).

TABLE 2.5 DISABILITY RATES OF THOSE AGED 3-5 YEARS BY TYPE AND COUNTY, CENSUS 2011

County	Persons with a disability	Blindness/deafness	Physical	Intellectual	Psychological/emotional	Other
Carlow	4.26%	0.36%	1.97%	1.85%	0.87%	2.72%
Cavan	3.28%	0.45%	1.36%	1.58%	0.31%	2.23%
Clare	3.77%	0.48%	1.39%	1.90%	0.49%	2.27%
Cork	4.57%	0.52%	1.93%	2.39%	0.71%	2.91%
Donegal	4.47%	0.70%	1.80%	2.07%	0.74%	2.89%
Dublin	4.42%	0.59%	1.73%	2.12%	0.60%	2.89%
Galway	4.00%	0.51%*	1.69%	2.01%	0.46%*	2.54%
Kerry	4.02%	0.32%	1.77%	1.99%	0.47%	2.81%
Kildare	4.28%	0.54%	1.59%	1.99%	0.47%	2.96%
Kilkenny	3.47%	0.42%	1.50%	1.69%	0.44%	2.25%
Laois	4.34%	0.56%	1.76%	1.99%	0.77%	3.07%
Leitrim	3.65%	0.20%*	1.49%	1.55%	0.47%*	2.16%
Limerick	5.40%	0.51%	2.17%	2.47%	0.84%	3.72%
Longford	3.97%	0.31%	1.44%	1.75%	0.57%*	2.89%
Louth	3.88%	0.45%	1.46%	1.66%	0.36%	2.72%
Mayo	3.57%	0.47%	1.34%	1.77%	0.33%	2.41%
Meath	3.86%	0.60%	1.63%	1.91%	0.52%	2.32%
Monaghan	3.25%	0.24%	1.36%	1.57%	0.45%	2.13%
Offaly	5.26%	0.61%	2.16%	2.79%	0.89%	3.15%
Roscommon	3.91%	0.65%*	1.66%	2.06%	0.62%	2.39%
Sligo	4.18%	0.71%*	1.57%	1.86%	0.71%	2.91%
Tipperary	4.31%	0.52%	1.82%	1.99%	0.66%	2.75%
Waterford	3.84%	0.42%	1.33%	2.05%	0.60%	2.27%
Westmeath	4.84%	0.84%	2.03%	2.43%	0.94%	2.75%
Wexford	4.13%	0.59%	1.75%	2.14%	0.47%	2.54%
Wicklow	3.99%	0.60%	1.45%	1.67%	0.49%	2.66%
State	4.25%	0.54%	1.71%	2.06%	0.59%	2.76%

Note: Counties with figures reported in **bold** are higher than the State average. Percentages marked with an asterisk (*) are estimates.

TABLE 2.6 DISABILITY RATES OF THOSE AGED 3-5 YEARS BY TYPE AND COUNTY, CENSUS 2016

County	Persons with a disability	Blindness/deafness	Physical	Intellectual	Psychological/emotional	Other
Carlow	4.95%	0.49%*	2.42%	2.91%	1.17%	3.33%
Cavan	4.16%	0.46%	2.08%	2.56%	0.78%	2.73%
Clare	4.05%	0.60%	2.22%	2.49%	0.86%	2.20%
Cork	4.82%	0.68%	2.59%	3.11%	1.05%	2.93%
Donegal	4.37%	0.72%	2.10%	2.34%	0.79%	2.72%
Dublin	4.56%	0.65%	2.16%	2.57%	1.01%	2.86%
Galway	3.76%	0.54%*	1.92%	2.19%	0.66%	2.47%
Kerry	4.49%	0.69%	2.37%	2.59%	0.86%	2.89%
Kildare	4.18%	0.65%	2.03%	2.20%	0.82%	2.71%
Kilkenny	4.15%	0.67%	1.85%	2.13%	0.96%	2.67%
Laois	5.47%	0.97%	2.69%	3.27%	1.22%	3.66%
Leitrim	3.59%	0.86%*	1.44%	2.01%	0.79%*	2.30%
Limerick	5.76%	0.70%	2.95%	3.28%	1.43%	3.71%
Longford	4.18%	0.60%	2.01%	2.22%	0.86%	2.52%
Louth	4.56%	0.64%	2.36%	2.63%	0.92%	2.97%
Mayo	4.11%	0.51%	1.97%	2.50%	0.79%	2.74%
Meath	4.45%	0.73%	2.09%	2.55%	0.92%	3.05%
Monaghan	4.07%	0.65%	2.29%	2.46%	0.92%	2.63%
Offaly	5.81%	0.81%	2.81%	3.53%	1.95%	3.42%
Roscommon	3.69%	0.39%*	2.31%	2.31%	0.64%	2.52%
Sligo	3.91%	0.50%	1.67%	2.31%	0.89%	2.35%
Tipperary	4.90%	0.54%	2.68%	2.90%	1.50%	3.19%
Waterford	4.73%	0.59%	2.21%	2.42%	0.89%	3.01%
Westmeath	4.75%	0.78%	2.50%	2.81%	0.97%	2.93%
Wexford	4.13%	0.65%	1.83%	2.26%	0.80%	2.73%
Wicklow	4.60%	0.53%	2.28%	2.56%	1.09%	3.20%
State	4.54%	0.64%	2.25%	2.62%	0.99%	2.89%

Note: Counties with figures reported in **bold** are higher than the State average. Percentages marked with an asterisk (*) are estimates.

2.4 COMPARISON OF CENSUS ESTIMATES AND GUI ESTIMATES OF CHILDHOOD DISABILITY

Table 2.7 compares estimates of childhood disability for those aged 3-5 years from the Census of Population (2016) and the GUI, with the latter drawn from teacher assessments at age 5.⁶ We focus on the teacher estimates because of all the GUI

⁶ Chapter 5 estimates the rate of disabilities and additional needs among young children in Ireland using the GUI dataset in more detail and illustrates how these rates vary under different definitions. Table A.2 in the appendix presents a more extensive set of disability and difficulty rates from the GUI that were also considered for the infant cohort (waves 2 and 3), as well as the teacher survey at age 5. Detailed definitions of specific rates can be found in Section 5.1.1, which examines the comparison of the estimates for different elements of the PCG, teacher assessments and diagnosis information.

sources, they are mostly closely aligned to the Census measures of disability and difficulty.

TABLE 2.7 COMPARISON OF CENSUS AND GUI ESTIMATES OF CHILDHOOD DISABILITY (%)

	Census of Population (3-5 years, 2016)	GUI teacher assessment (age 5, 2013)
Blindness, vision impairment, deafness or a serious hearing impairment	0.64%	3.20%
A difficulty with basic physical activities	2.25%	
An intellectual disability, difficulty with learning, remembering or concentrating	2.62%	1.39% ASD 2.94% Mild general learning disability (GLD) 0.85% Moderate, severe, profound GLD 0.98% Specific learning difficulty, e.g. dyslexia
A psychological or emotional condition	0.99%	2.64% Emotional or behavioural, e.g. ADD, ADHD
Other disability, including chronic illness	2.89%	0.85% Other limitation to activity 0.61% Other limiting medical or health problem 0.43% Other motor skills, dyspraxia
Speech problems		7.63% Speech difficulty
Total (any of above)	4.54% (9,587)	15.55% (1,301)
Total excluding speech difficulty or mild GLD	4.54% (9,587)	8.82% (738)

Source: Census 2016 and GUI '08 5 years (wave 3).

Note: GUI estimates are weighted using the survey weights at 5 years.

In the teacher survey, each measure of disability refers to limitations affecting the child (5 years) at school. In order to allow a direct comparison with the categories of disability in the Census of Population (matching to the greatest degree possible), we recommend using the total figure for the GUI teacher survey at age 5, excluding issues with speech or a mild learning disability. This measure covers five broad facets of disability and other difficulties, physical, visual, and hearing impairment, learning difficulties, emotional or behavioural difficulties, and other broader difficulties. As speech measures do not feature in the Census definition of disability, the GUI teacher survey aligns most closely to the Census rate.

The GUI overall estimate of childhood disability is 8.8 per cent, compared to the total childhood disability rate estimate from the Census (2016) of 4.5 per cent. This indicates a factor increase of approximately 1.9 times. The categories examining blindness, deafness and difficulties with physical activities closely align across the

two estimates, at approximately 3 per cent. The GUI estimates for intellectual disabilities considers 'autism spectrum disorders', 'general learning disabilities', and 'specific learning difficulties'. These measures are higher in the GUI than in the Census, which may be due to differences in age at diagnosis, which is at 5 years for the GUI source – after entering the Early Childhood Care and Education (ECCE) or school – compared to 3-5 years for the Census. Furthermore, primary caregivers (PCGs) who will most likely have completed the Census may not report in the same way as teachers, given the stigma which can be attached to having a disability. Conversely, as discussed above, the 'other' rate is significantly greater in the Census than the 'other' categories recorded in the GUI teacher assessments. This is because the relevant questions in the GUI are somewhat broader than those found in the Census.

The GUI estimate for speech difficulties among 5 year olds is 7.6 per cent. For these data, teacher respondents were asked whether they believed the child in question had a 'speech impairment'. Since this specific measure does not appear in the Census, we omit it from this analysis.

We would expect the GUI rate of disability to be higher than the Census estimate of disability given the differing age profiles (3 years for the GUI survey versus 3-5 years for the Census). Differences or difficulties a child may face can become more apparent upon their entering the education system and being among their peers. A prime example of this would be the category of mild learning difficulties, which may not be evident before children are of school age. Furthermore, teachers may be more objective in reporting disability; parents might downplay difficulties due to stigma, or conversely they might overstate difficulties due to concerns about behaviour or future development.

2.5 SUMMARY

The childhood disability rate increased from 4.3 per cent in 2011 to 4.5 per cent in 2016. This was driven by a larger increase in the number of children with disabilities aged 3-5 years relative to the increase in the population aged 3-5 years. In 2016, the incidence of childhood disability ranged from 3.6 per cent in Leitrim to 5.8 per cent in Offaly. The disability rate increased between 2011 and 2016 in all but seven counties: Donegal, Galway, Kildare, Leitrim, Roscommon, Sligo and Westmeath.

Across the State, all types of disability increased between 2011 and 2016, albeit to varying degrees. The disability categories of psychological and/or emotional conditions, intellectual disabilities and physical disabilities all increased significantly, while other types saw more modest growth over the period. Disability rates by type at a county level increased for the most part between 2011 and 2016 with a few exceptions. Intellectual disabilities and psychological/emotional conditions increased in all counties between 2011 and 2016.

To put our findings on Census estimates of childhood disability in context, given the difficulties associated with measuring disability, this chapter also looks at the prevalence of children with disabilities according to the GUI study. The GUI estimate of childhood disability overall is 8.8 per cent compared to the total childhood disability rate estimate from the Census (2016) of 4.5 per cent. This indicates a factor increase of approximately 1.9 times. This is to be expected given that the GUI cohort is 5 years, compared to the Census one of 3-5 years, as there is likely to be a significant age gradient associated with disability. Furthermore, teachers may be more likely to spot difficulties children face, given both their professional experience with children and the opportunity their role affords them to observe children interact with peers of the same age.

CHAPTER 3

Examination of AIM programme provision

3.1 INTRODUCTION

Under the Early Childhood Care and Education (ECCE) programme, since September 2018 all eligible children in the Republic of Ireland have been able to benefit from free early childhood care and education for two years before they start primary school. The European Commission (2013) has stressed the importance of providing access to affordable quality early childhood education and care as a means of combating poverty and social exclusion and preventing intergenerational transmission of disadvantage (European Commission, 2013). This is supported by widely cited research by Heckman (2006), which argues that the most effective way to address socio-economic deficits is to invest more heavily in the early development of children from disadvantaged backgrounds. Therefore, the availability of the ECCE programme represents a key policy tool in efforts to alleviate social inequalities.

This chapter examines data from the Access and Inclusion Model (AIM) programme, which is the main initiative in Ireland designed to facilitate children with disabilities in accessing mainstream early years provision for pre-school children. The objective of the analysis is to examine the extent to which such provision is evolving over time and the degree to which it aligns with the spatial distribution of childhood disability.

3.2 THE ACCESS AND INCLUSION MODEL (AIM)

AIM was introduced in order to support children with a disability to access and participate in the 'free preschool' initiative. The model is a cross-government, collaborative initiative, with implementation shared across a number of different bodies, including the Department of Children, Equality, Disability, Integration and Youth (DCEDIY), the Department of Education, the Department of Health, Health Service Executive (HSE), Pobal and Better Start. AIM uses a child-centred approach and is designed to ensure that children with disabilities can access and meaningfully participate in the ECCE programme in mainstream pre-school settings alongside their peers.⁷ The model (outlined in Figure 3.1) offers bespoke supports based on participating children's individual needs and the pre-school setting and does not require a formal diagnosis of disability.

⁷ AIM considers disability to be defined as 'a long-term physical, mental, intellectual or sensory impairment which, in interaction with various barriers, may hinder a child's full and effective participation in society on an equal basis with others' (Department of Children, Equality, Disability, Integration and Youth, 2020).

FIGURE 3.1 ACCESS AND INCLUSION MODEL (AIM) FRAMEWORK

Source: Policy on the operation of the AIM programme (2016)

There are seven levels of support provided, which range from universal to targeted depending on the needs of the child and their pre-school setting. Levels 1–3 (universal supports) are designed to support an inclusive culture within the pre-school setting, using various education and capacity-building initiatives. Level 4–7 (targeted supports) provide for additional support in cases where the pre-school provider and primary caregiver (PCG) consider that some additional more targeted supports are required to meet the needs of a particular child. We consider children who access the targeted supports (that is levels 4–7), because all children (with or without disabilities) may benefit or at least have access to the universal supports. Applications for the targeted supports at the time these data were gathered were made by the pre-school provider, in partnership with a PCG, via the Programmes Implementation Platform (PIP) on the Pobal website. Pobal processes the applications for additional supports and informs the PCG and pre-school provider when a decision has been made. The specific levels that such targeted supports can take are summarised as:

- (i) expert early childhood care and education, advice and mentoring through early years specialists (Level 4);
- (ii) specialised equipment, appliances or capital grants towards minor building alterations (Level 5);
- (iii) arrangements made with the HSE for the provision of therapeutic services such as psychology, occupational therapy, speech and language therapy (Level 6); and
- (iv) an additional capitation to fund extra support in the classroom or enable the reduction of the child-to-staff ratio (Level 7).

Level 7 supports are granted when it is deemed critical to ensuring a child's meaningful participation in the ECCE programme in their pre-school setting. There are two different rates of capitation payable, depending on the complexity of the difficulties faced by individual children in fully participating in early childhood care and education. In 2016, when AIM was introduced, it was estimated that approximately 3.5 per cent of ECCE children would have a disability while 1 to 1.5 per cent of ECCE children would require additional supports through the AIM programme.

AIM uses an agreed definition of complex and additionally complex needs in the context of preschool participation. Complex needs are outlined as an exceptional level of need requiring access to HSE children's disability teams or specialist teams; for example, this might be an enduring physical impairment or disability and/or severe or profound learning difficulties and non-verbal communication and/or moderate to severe hearing loss and/or severe behavioural difficulties. Additionally, complex needs are outlined as highly significant difficulties arising from enduring physical, sensory, social, communication, learning, medical, emotional or behavioural needs which have been assessed as complex, where additional adult assistance has been determined as needed to deliver intensive interventions and individualised support and where, without such assistance, participation in pre-school would not be meaningful or safe. Complex medical needs are understood to mean the complex needs above and alongside specific factors giving rise to particular medical needs or risks for a child; for example, complex health conditions requiring medical support such as anti-seizure treatment, intravenous feeding or serious allergy. Complex medical care often requires specific training to meet the child's individual health needs; examples here include tracheotomy care, seizure management, tube feeding or other specialised medical procedures. In 2019, a trial initiative began for such cases whereby DCEDIY-funded nursing hours would be provided.

3.3 PIP DATASET

Data from the PIP was utilised to examine the AIM programme provision. PIP is an online administration system that was developed in order to streamline the process of implementing the three National Childcare Funding Programmes: (i) Early Childhood Care and Education (ECCE) scheme; (ii) Community Childcare Subvention (CCS) scheme; and (iii) Training and Employment Childcare (TEC) programmes. It was established in 2014, with the aims of reducing the paperwork associated with the ECCE, CCS and TEC programmes, simplifying administration and enabling the programmes to be managed more effectively and efficiently. The PIP system is managed by Pobal on behalf of the DCEDIY.

In relation to the AIM programme, we reviewed an outline of all the variables and a document outlining the data mapping description of the PIP dataset. Pobal then provided data detailing a count of the children availing of assistance through the targeted interventions of AIM in 2016 (launch year of the programme) and in 2019, with a further breakdown by county. Using these PIP data, here we superimpose the regional utilisation of AIM onto the analysis of the Census data on the prevalence of disability among young children (age 3-5) at a regional level (as per Chapter 2) to assess the extent to which disparities exist between prevalence of disability and current levels of support.

PIP data show there were 2,316 children benefiting from targeted AIM supports across Ireland in 2016, a figure that had risen to 5,725 by 2019.

3.4 SPATIAL ANALYSIS OF AIM PLACES BY COUNTY, 2016 AND 2019

Figure 3.2 plots the number of children benefiting from the AIM programme divided by the estimated number of children aged 3-5 years with a disability at county level in 2016. This provides us with a broad indicator of utilisation of AIM targeted supports among children with disabilities. It is important to note that participation in AIM is voluntary and relies on an application being made to the services. Furthermore, some children with disabilities will be able to participate fully in ECCE via the universal supports; for them, further intervention will therefore not be needed. For these reasons, it would never be expected that 100 per cent of children with disabilities avail of targeted AIM supports; there is not even a clear sense of the most appropriate rate of utilisation for such a programme. Nevertheless, by examining the change in estimated utilisation of the programme over time, we get a sense of changes in both programme capacity and the awareness of the initiative among PCGs and early years providers.

It is also important to note that we do not distinguish how AIM provision is divided across the varying levels of support available; instead, we look at the number of children availing of targeted AIM supports, some of whom benefit from one level of support while others benefit from more than one level, depending on their needs.

In 2016, the number of children availing of targeted AIM supports, across most counties, equated to between 13 per cent and 43 per cent of the estimated number of children with disabilities aged 3-5 years. Figure 3.2 standardises the number of children availing of AIM in 2019 by the number of children aged 3-5 years with a disability in each county during 2016. While the use of 2016 disability levels (from the Census of Population) will be less accurate for 2019, they will still give a good indication of the change in county-level rates of AIM support as the relevant demographics tend to change very slowly over time. Furthermore, in the absence of any Census data post-2016, this is the best strategy available to us. In 2019, the situation appears to have changed radically, with all counties having between 45

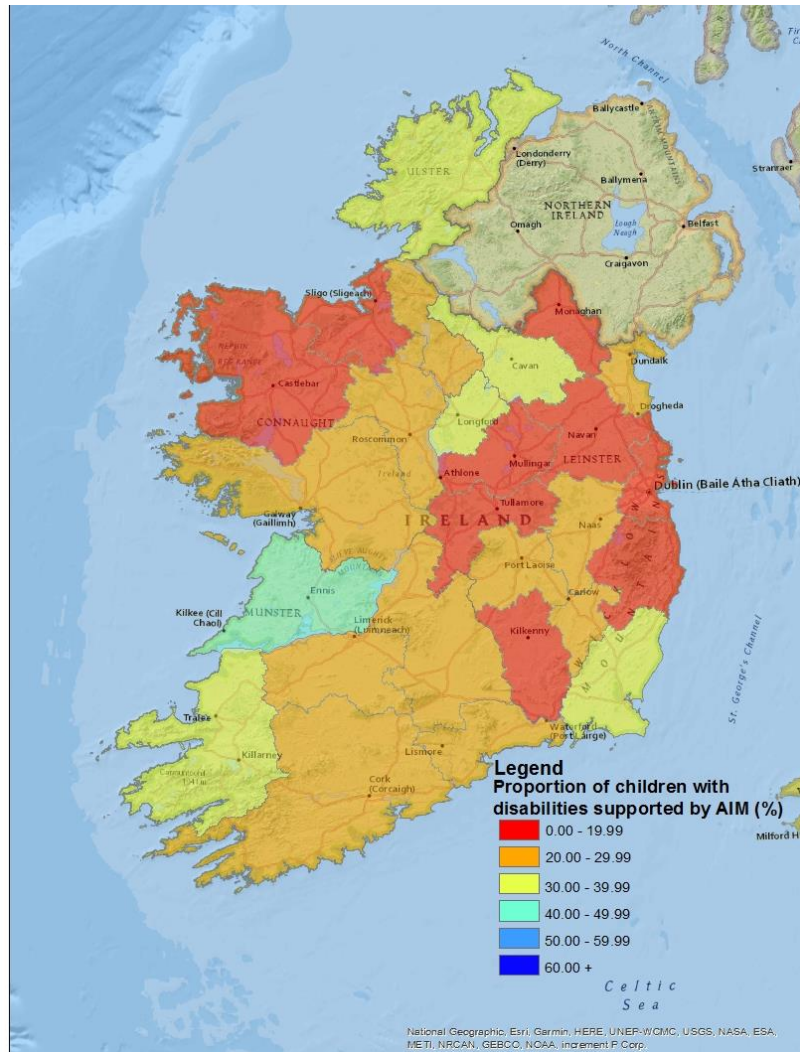
and 79 per cent of children with disabilities benefiting from targeted AIM supports, pointing to a rapid expansion of engagement with the programme from both PCGs and service providers over the period from the launch of the programme in 2016 up to 2019.

Those counties which had the lowest rates of children with disabilities benefiting from targeted AIM supports in 2016 had seen the largest increases by 2019. In particular, in Offaly, the proportion of children aged 3-5 years with disabilities availing of targeted AIM supports increased from 14 per cent in 2016 to 65 per cent in 2019. Dublin, Louth, Monaghan, Meath, Wicklow and Mayo all also saw the proportion of those benefiting from targeted AIM supports more than triple over the same three-year period. Longford, where the proportion of children with disabilities utilising AIM supports increased from 37 to 52 per cent, was one of only four counties that didn't see the rate at least double, the other three being Clare, Donegal and Cavan. At state level, the proportion of children with disabilities accessing the targeted AM supports increased from 22 per cent in 2016 to 60 per cent in 2019.

The large increases in utilisation of the programme by children with disabilities over time is in part down to the nature of the programme and the length of time required for some supports to be put in place; staff training is one such example. This was recognised from the outset of the programme, as noted on the programme's website: 'while the Access and Inclusion Model was introduced in June 2016, full implementation will take time as capacity is built across the sector'.⁸ Increased awareness of the programme among PCGs of children aged 3-5 years and service providers, as well as those who may provide advice to families of children with disabilities, is also likely to have contributed to the increased proportion of children with disabilities availing of supports by 2019.

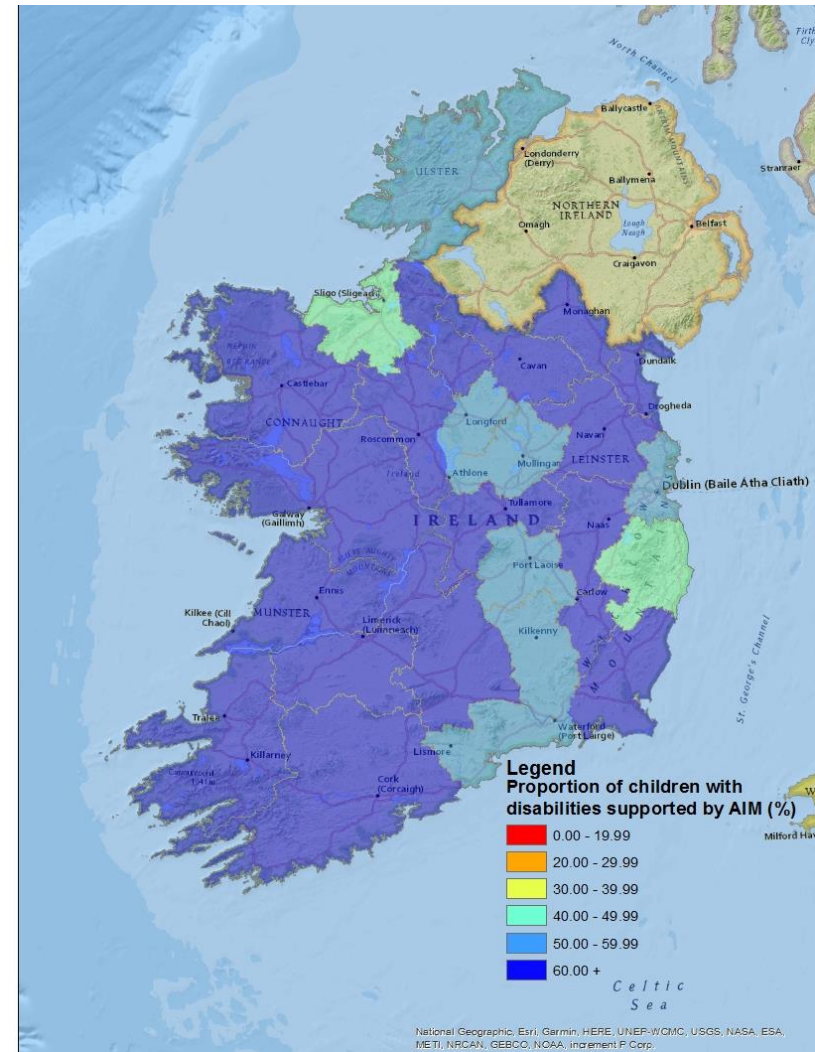
⁸ See <https://www.aim.gov.ie/>.

FIGURE 3.2 SPATIAL ANALYSIS OF AIM-SUPPORTED CHILDREN, 2016



Source: PIP and Census data.

FIGURE 3.3 SPATIAL ANALYSIS OF AIM-SUPPORTED CHILDREN, 2019



Source: PIP and Census data.

3.5 SUMMARY

This chapter looks at how the population of children benefiting from targeted AIM supports differs spatially across Ireland relative to the population of children with disabilities. At county level, between the implementation of the programme in 2016 and 2019, the proportion of children with disabilities supported by the AIM programme increased considerably.

To reiterate, participation in AIM is voluntary and relies on an application being made to the services by those in need of further support. Furthermore, not all children with disabilities will need further support to engage fully with the ECCE programme. For these reasons, utilisation would never be expected to approach 100 per cent; there is not even a clear sense of the most appropriate rate of uptake for such a programme. Nonetheless, such stark regional variation in the proportion of children with disabilities supported by AIM, which we have shown here, may be concerning and may point to there being unmet need in some counties. If we assume that the ratio of support need to disability prevalence is geographically neutral we would expect all counties to have a similar proportion of children with disabilities benefiting from targeted AIM supports. A beneficial short-term objective may be to increase the proportion of children with disabilities benefiting from AIM targeted supports in all counties closer to the current maximum of 79 per cent in Louth.

CHAPTER 4

Evolution of need

4.1 INTRODUCTION

This chapter examines the evolution of need at a regional level in the short to medium term. We briefly outline the ESRI regional demographic model and the demographic trends that drive population projections. Given the key importance of fertility for this exercise, we produce two different scenarios reflecting different assumptions on how fertility may behave in the medium term. Finally, we combine the shares of child disability calculated in the previous chapter with population projections for the relevant ages to produce a projection of the number of children with disabilities up to the year 2030 at a county level.

4.2 ESRI REGIONAL DEMOGRAPHIC MODEL: METHODOLOGY

The ESRI regional demographic model follows the cohort component method, which is the most widely used methodology to produce population projections.⁹ The model projects the population by gender and single year of age at a county level for each year over the medium to long term. This method follows two simple equations to generate the population aged i for county j at time t :

$$P_t^{i,j} = (1 - d_{t-1}^{i-1}) * P_{t-1}^{i-1,j} + nEM_t^{i,j} + nIM_t^{i,j}, \text{ for } i > 0$$

$$P_t^{0,j} = B_t^j + nEM_t^{0,j} + nIM_t^{0,j}$$

The first equation shows that the population aged i in county j , $P_t^{i,j}$, in a given year is simply the surviving population $1 - d_{t-1}^{i-1}$, where d_{t-1}^{i-1} is the age-specific mortality rate, applied to the the previous years' population ($P_{t-1}^{i-1,j}$) plus net international ($nEM_t^{i,j}$) and internal migration ($nIM_t^{i,j}$) of the population aged i . The second equation is for the population aged less than one, so instead of the

⁹ For a full description of the model, see Bergin and García-Rodríguez (2020). The estimates of Bergin and García-Rodríguez (2020) were developed before the Covid-19 pandemic. To evaluate the potential impact of the pandemic on the demographic projections, we have to consider the potential impact on each of the underlying demographic assumptions. For example, although the pandemic has resulted in some increase in mortality, it is concentrated at older age groups and has had limited impact on children or women of fertile age. Hence, the impact on the projections in this report will be minor. On fertility, there was a slight decline in births in 2020 (-6.4% year-on-year versus -2.7% on average for 2012-2019), potentially decreasing the likelihood of the high fertility scenario, if this trend were to persist over the medium term. There are currently no data on the impact of the pandemic on internal migration patterns and the permanence of any such impacts. Early studies in the US (Ramani and Bloom, 2021) show some relocation away from city centres to suburban rings but not across cities, with the results driven by firms moving to hybrid arrangements and not fully remote working. We would expect these movements to produce a minor spatial reallocation away from Dublin, which may impact the number of children with disabilities in that county without altering the national figure. Finally, international migration has been severely disrupted by the pandemic, although we do not know if this will be a transitory or permanent phenomenon, and again we adopt a more benign medium-term assumption for international migration.

surviving population it uses the number of births in the county B_t^j . The cohort component model, therefore, uses a detailed snapshot of the population as a starting point and then projects it into the future following assumptions on the drivers of population change, namely mortality, fertility and migration (both international and internal). Our starting point is the 2016 Census, which provides the population by single year of age and gender at a county level.

To project the population forward, we need projections on mortality, fertility, international migration and internal migration. As we will use two different assumptions on fertility to create different scenarios, we discuss them in depth in the next section.

For mortality, we follow the mortality assumptions of the Central Statistics Office's (CSO) recent national and regional projections (see CSO, 2018 and CSO, 2019a). Based on recent trends on mortality, the CSO projects an increase in life expectancy at birth for males from 79.3 years in 2015 to 82.7 years in 2031 and for females from 83.3 in 2015 to 85.9 years in 2031. An age- and gender-specific profile of mortality rates is developed for the projection horizon and these rates are applied at a county level, uniformly for all counties.

For international migration, we use the latest estimates from the CSO, which are available up to 2020. The latest CSO estimates of net international migration for 2017, 2018 and 2019 are +19,800, +34,000 and +33,700 respectively. After that, we assume net international migration declines linearly to +15,000 by 2024 and remains constant thereafter. The medium-term figure is based on updated projections from the Economic Outlook (see Bergin et al., 2016) and is consistent with expected economic conditions in Ireland and abroad. The national figure is distributed among the counties according to their historical averages, as migrants tend to locate in the main cities, particularly Dublin. In the last two Censuses, the top three destinations for net international migration were: Dublin, with 43.6 per cent; Cork, with 10.9 per cent; and Galway, with 5.8 per cent. Finally, we apply an age profile to the number of migrants allocated to each county to reflect the fact that international migration tends to be composed of people of prime working age, between 20 and 45 years old. From the last Census, around 47 per cent of international migrants were aged between 20 and 30 years and a further 27 per cent between 31 and 45.

The most innovative element of the ESRI demographic model is its treatment of internal migration. Internal migration between counties in Ireland has been characterised in the last 30 years by two alternating patterns: Dublin flipping between creating large outflows towards its surrounding counties and Dublin being

a net receiver of people from the rest of Ireland.¹⁰ These patterns are determined by changes in underlying economic conditions, in particular the evolution of house prices in Dublin relative to the rest of the country. Therefore, to create projections for internal migration, we combine an analysis of how variables like population, house prices and labour market conditions affect the movements of people between counties and projections of these economic variables. If current economic trends continue, we project a pattern very similar to that of 2016, which represented a softer version of the Dublin Outflow model. There is an average net outflow from Dublin of a little over 6,000 people per annum, going mostly to the counties around Dublin, and with most of the rest of the country picking up small net gains of internal migrants.

4.3 FERTILITY RATES AND SCENARIOS

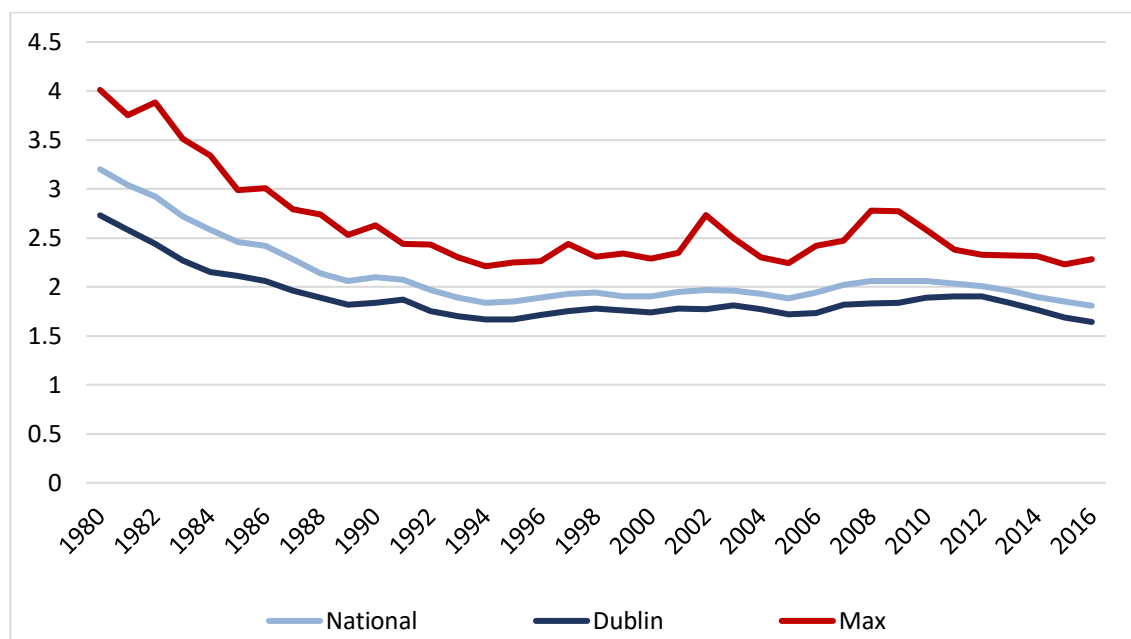
Fertility rates represent the last element needed to create projections with the demographic model. As fertility rates are a key element in projecting the very young population, we use two different assumptions on fertility rates to create two different scenarios. These assumptions are based on historical patterns, which we describe below.

4.3.1 Historical trends on fertility

The total fertility rate (a measure of the number of children that a representative woman will have over her lifetime) at a national level saw a marked decline starting in the early 1980s, going from over three to just under two by the mid-1990s and remaining broadly stable since then (see Figure 4.1).¹¹ The data also show differences in fertility rates at a regional level. For example, Dublin generally has the lowest fertility rate over time and the gap between the rate in Dublin and the national average shows no sign of converging over time.

¹⁰ For example, in 1996 a total of 56,710 people moved between counties, with Dublin registering a net positive internal migration of 2,055 people. On the other hand, in 2006 there were 87,989 internal movers and Dublin saw a net negative flow of 10,213 people.

¹¹ Specifically, the total period fertility rate represents the theoretical average number of children who would be born alive to a woman during her lifetime if she were to pass through her child-bearing years (ages 15-49) conforming to the age-specific rates of a given year. The rate refers to a theoretical female cohort.

FIGURE 4.1 TOTAL PERIOD FERTILITY RATE

Source: CSO, Vital Statistics.

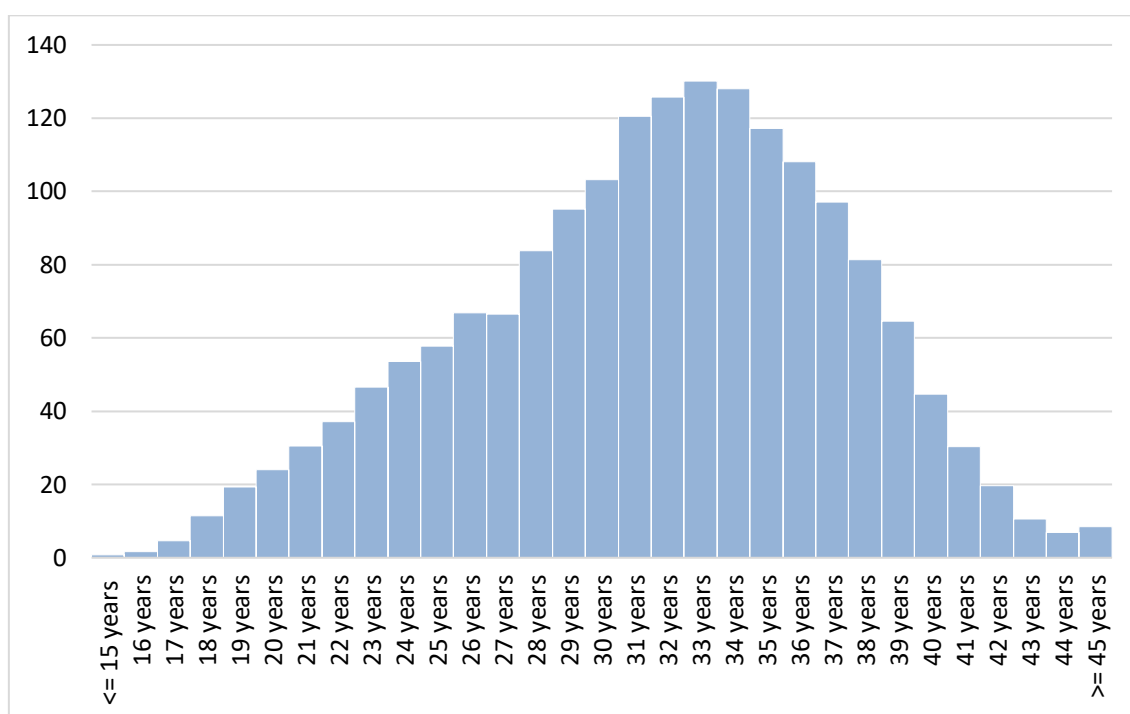
An analysis of county-level fertility rates over time shows there is a lot of variation in fertility rates across counties, as can be seen in Table 4.1. For example, in 2016 while the national total fertility rate was 1.81, fertility rates across Ireland were as low as 1.64 in Dublin and as high as 2.28 in Longford. The historical data show that these differences in fertility rates across counties persist over time so that individual counties tend to consistently have either high or low fertility rates.

TABLE 4.1 FERTILITY RATES BY COUNTY, 1996-2016

	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016
Dublin	1.71	1.75	1.78	1.76	1.74	1.78	1.77	1.81	1.77	1.72	1.73	1.82	1.83	1.84	1.89	1.90	1.90	1.84	1.76	1.69	1.64
Kerry	1.90	1.96	1.91	1.84	1.84	1.88	1.95	1.84	1.90	1.81	1.93	2.05	2.00	2.10	1.87	2.01	1.93	1.84	1.78	1.75	1.81
Monaghan	1.96	1.88	1.91	1.96	1.77	1.71	1.86	1.81	1.75	1.87	1.80	1.95	2.03	1.94	2.03	2.01	2.00	2.03	1.94	1.96	1.93
Kilkenny	1.86	1.93	1.92	1.83	1.91	1.99	1.97	1.96	1.90	1.85	1.87	1.94	2.07	2.04	2.08	2.03	2.02	1.94	1.91	1.78	1.72
Sligo	1.94	1.92	2.02	1.84	1.84	1.88	1.82	1.85	1.81	1.72	2.01	2.04	2.08	2.12	1.99	2.01	2.21	2.04	1.87	1.84	1.83
Cork	1.89	1.94	1.99	1.83	1.85	1.88	1.95	1.90	1.90	1.88	1.96	2.01	2.07	2.10	2.08	2.02	1.99	1.95	1.87	1.88	1.75
Galway	1.89	2.01	2.07	2.02	2.03	2.10	1.96	1.94	1.93	1.87	1.86	1.96	2.07	1.96	2.01	1.96	2.01	1.96	1.85	1.81	1.83
Donegal	2.05	2.11	2.05	2.10	1.95	2.03	2.00	2.02	1.89	1.91	1.95	1.98	2.00	2.07	1.94	1.96	1.97	1.87	1.78	1.91	1.93
Limerick	2.05	2.08	2.06	1.93	1.87	1.81	1.87	1.95	1.86	1.81	1.94	2.04	2.11	2.16	2.13	2.09	2.00	1.97	1.94	1.97	1.89
Roscommon	1.82	1.90	1.93	1.77	1.68	1.82	1.95	1.89	1.98	2.06	2.01	2.04	2.27	2.27	2.28	2.02	2.10	2.21	1.99	1.92	1.93
Louth	1.88	1.99	2.03	2.05	2.10	2.30	2.06	1.92	1.92	1.83	1.97	1.93	2.04	1.94	2.00	1.99	2.09	2.24	1.98	2.05	1.99
Waterford	1.99	1.94	1.90	1.92	1.93	2.09	2.21	2.09	2.06	1.97	2.18	2.18	2.27	2.15	2.14	2.15	2.04	2.09	2.06	1.99	1.97
Offaly	2.10	2.07	2.22	1.98	1.85	2.13	2.23	2.02	2.12	2.02	2.09	2.09	2.14	2.15	2.06	2.23	2.09	1.98	2.18	1.94	1.98
Mayo	2.11	2.12	2.15	2.09	2.09	2.09	2.01	2.08	1.93	2.00	2.10	2.25	2.21	2.10	2.15	2.13	2.17	2.19	2.06	1.99	2.02
Tipperary	2.09	2.15	1.94	1.99	2.02	1.98	1.97	2.04	2.04	2.11	2.04	2.26	2.26	2.34	2.22	2.17	2.04	2.14	2.04	2.09	2.05
Wicklow	2.01	1.96	2.00	2.03	2.02	2.03	2.16	2.07	2.09	1.92	2.21	2.28	2.32	2.30	2.35	2.18	2.19	2.13	2.05	2.02	1.96
Clare	2.01	2.16	2.08	2.27	2.08	2.19	2.34	2.26	2.16	2.10	2.16	2.15	2.18	2.28	2.03	2.08	2.08	1.89	1.88	2.03	1.96
Laois	2.00	2.07	2.10	2.06	2.04	2.15	2.26	2.30	2.30	2.04	2.11	2.37	2.42	2.50	2.50	2.12	2.03	1.94	1.95	1.96	1.84
Westmeath	2.13	2.14	2.11	2.26	2.29	2.33	2.19	2.17	2.14	2.10	2.22	2.13	2.16	2.17	2.16	2.11	2.11	2.14	2.15	2.00	2.03
Kildare	2.09	2.14	2.18	2.07	2.27	2.31	2.34	2.23	2.20	2.00	2.16	2.31	2.29	2.32	2.29	2.16	2.11	2.02	2.02	1.97	1.93
Leitrim	2.09	2.05	2.10	2.20	2.02	1.92	2.29	2.26	2.25	2.21	2.17	2.45	2.50	2.38	2.27	2.15	2.15	2.23	2.00	2.11	2.17
Meath	1.98	2.05	1.99	2.04	2.09	2.35	2.20	2.33	2.28	2.22	2.16	2.41	2.39	2.35	2.39	2.33	2.14	2.21	2.08	1.99	1.99
Wexford	2.10	2.16	2.19	2.24	2.09	2.21	2.21	2.34	2.27	2.20	2.26	2.29	2.44	2.29	2.18	2.20	2.17	2.05	2.13	2.05	1.95
Carlow	2.06	1.84	2.16	1.98	2.22	2.24	2.40	2.33	2.14	2.16	2.21	2.47	2.59	2.36	2.35	2.38	2.30	2.09	2.32	2.02	1.90
Cavan	2.18	2.44	2.21	2.34	2.10	2.14	2.19	2.09	2.16	2.14	2.29	2.33	2.60	2.52	2.49	2.38	2.29	2.22	2.08	2.09	2.12
Longford	2.26	2.27	2.31	2.20	2.20	2.35	2.73	2.50	2.24	2.24	2.42	2.38	2.78	2.77	2.58	2.31	2.33	2.32	2.16	2.23	2.28

Sources: CSO and Department of Health.

Figure 4.2 shows the prevailing age-specific fertility rates by year of age for women. The age-specific fertility rate measures the annual number of births to women of a specified age per 1,000 women of that age. The graph indicates that fertility rates increase steadily with age and peak between 31 and 35 years before falling sharply for women beyond this age group.

FIGURE 4.2 AGE-SPECIFIC FERTILITY RATES BY SINGLE YEAR OF AGE, 2016

Source: CSO, Vital Statistics.

Note: The age-specific fertility rate for a particular year of age is the number of live births to women of that age per 1,000 females of the same year of age.

4.3.2 Fertility scenarios

Based on the trends described above, we proposed two different scenarios. In the ‘baseline’ scenario, the overall total fertility rate (TFR) is assumed to decrease from 1.8 in 2016 to 1.6 in 2031 and remain constant thereafter. This profile matches the ‘low variant’ or F2 assumption used by the CSO (see CSO, 2018 and CSO, 2019b) in their population projections. Starting with county-level TFRs, the reduction in the overall TFR is applied proportionally to all counties. This ensures the national pattern shown in Table 4.1 is maintained over the projection horizon (i.e. counties that historically have had higher TFRs will continue to have comparatively higher TFRs over the projection horizon and vice versa). In a similar way, age-specific fertility rates (ASFRs) are adjusted proportionally with the headline decline of the overall TFR and applied to each county so that the ASFRs add up to their projected TFR. In the ‘high fertility’ scenario, the TFR is assumed to remain constant at 1.8. As the national figure remains unchanged, we also keep the differences between counties and the ASFR at their current levels. This scenario matches the ‘high variant’ or F1 assumption used by the CSO.

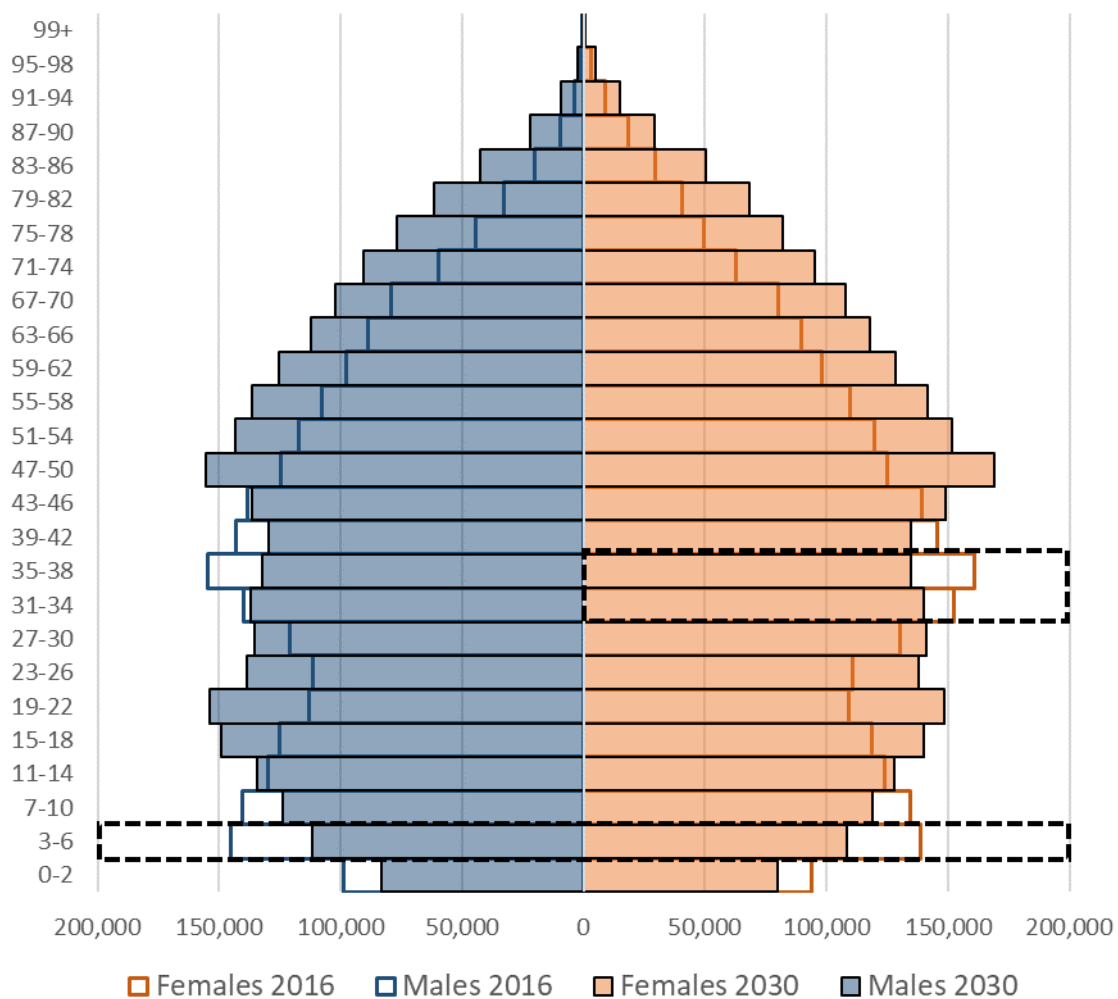
4.4 NATIONAL PROJECTIONS

Based on the demographic trends described above, in the ‘baseline’ scenario the population at the national level is projected to grow from 4.74 million in the 2016 Census to 5.20 million in 2025 and 5.37 million in 2030. In the ‘high fertility’ scenario, the figures would be 5.22 and 5.42 million, respectively. These 2030

figures imply an overall population growth of 0.9 per cent on an annual average basis in the baseline scenario and a 1.0 per cent in the high fertility scenario, a slowdown with respect to the 1.3 per cent annual average growth during the 1996 to 2016 period.

In the baseline scenario, the population aged 3-5 years is projected to decrease from 211,300 in 2016 to 175,000 in 2025 and 163,100 in 2030. For the high fertility scenario, those figures would be 181,900 and 176,600 in 2025 and 2030, respectively. The main explanation for this decrease can be seen in Figure 4.3, which presents the population pyramid for the years 2016 and 2030. The lower box shows the decrease in the 3-6 years population, explained by the decrease in females of ages 31 to 38, captured in the upper box. As we saw in Figure 4.2, females in that age group register some of the highest ASFRs in the latest data.

FIGURE 4.3 POPULATION PYRAMID, 2016-2030 (BASELINE SCENARIO)



Source: Authors' calculations.

Combining the projections for the population aged 3-5 years with the disability shares developed in the previous chapters, we can produce projections for children

with disabilities of the aforementioned ages. The results are summarised in Table 4.2. As expected, given the described evolution of the population of those aged 3-5 years, the number of children with disabilities is projected to trend downward to a range between 7,400 and 15,600 by 2030, depending on the assumptions on fertility and disability. The wide range in the projections is due to the large difference in disability rates between the Census and the GUI estimates. As shown above, the difference between the baseline and the high-fertility scenario of the population aged 3-5 years by 2030 is just 8.3 per cent (163,000 vs 176,000), while the difference in disability rates applied to these population figures is almost double (8.82% vs 4.54%).

TABLE 4.2 NATIONAL PROJECTIONS FOR CHILDREN AGED 3-5 YEARS WITH DISABILITIES, 2016, 2025 AND 2030

	Projection from Census data	Baseline/Low-fertility scenario		High-fertility scenario	
		2016	2025	2030	2025
Census disability share (4.54%)	9,600	7,900	7,400	8,300	8,000
GUI disability share, excluding speech issues (8.82%)	18,600	15,400	14,300	16,000	15,600

Sources: Authors' calculations.

Notes: Numbers rounded to the nearest hundred.

4.5 REGIONAL PROJECTIONS

At the regional level, as expected, the counties that are projected to have the largest number of children aged 3-5 years will also have the largest number of children with disabilities. As can be seen in Table 4.3, by 2030, the largest populations aged 3-5 years are projected to be in Dublin, with between 48,700 and 52,700 children depending on the scenario, followed by Cork with between 18,700 and 20,200 children, and Galway with between 8,500 and 9,200.

TABLE 4.3 REGIONAL PROJECTIONS FOR CHILDREN AGED 3-5 YEARS, 2025 AND 2030¹²

	Census	Baseline/Low-fertility scenario		High-fertility scenario	
	2016	2025	2030	2025	2030
Carlow	2,600	2,200	2,200	2,300	2,300
Cavan	3,700	2,900	2,700	3,000	2,900
Clare	5,100	3,800	3,700	4,000	4,000
Cork	24,000	19,700	18,700	20,500	20,200
Donegal	7,000	5,000	4,900	5,200	5,300
Dublin	56,200	54,400	48,700	56,500	52,700
Galway	11,300	9,100	8,500	9,400	9,200
Kerry	5,900	4,600	4,500	4,800	4,900
Kildare	11,300	8,900	8,300	9,200	9,000
Kilkenny	4,700	3,300	3,200	3,500	3,400
Laois	4,300	3,300	3,100	3,500	3,300
Leitrim	1,400	1,000	1,000	1,100	1,100
Limerick	8,400	6,900	6,600	7,200	7,200
Longford	2,000	1,700	1,600	1,700	1,700
Louth	6,100	4,600	4,300	4,800	4,700
Mayo	5,300	3,900	3,600	4,000	3,900
Meath	10,400	7,400	7,000	7,700	7,600
Monaghan	2,900	2,000	1,800	2,100	2,000
Offaly	3,600	2,800	2,800	2,900	3,000
Roscommon	2,800	2,000	1,900	2,000	2,100
Sligo	2,800	2,100	2,100	2,200	2,300
Tipperary	6,900	5,300	5,000	5,500	5,500
Waterford	4,900	3,900	3,700	4,100	4,000
Westmeath	4,100	3,400	3,300	3,600	3,500
Wexford	6,600	5,500	5,200	5,700	5,600
Wicklow	6,800	5,000	4,800	5,200	5,200

Source: Authors' calculations.

Note: Numbers rounded to the nearest hundred.

More interestingly, Figure 4.4 shows the share of the population aged 3-5 years out of total population by county, with darker shades representing larger shares and vice versa. By this metric, by 2030, the three largest shares are projected in Longford (with a share of between 3.4 per cent and 3.6 per cent depending on the scenario), Carlow (3.3%–3.5%) and Westmeath (3.2%–3.5%) and the smallest in Kerry (2.7%–2.9%), Roscommon (2.7%–2.9%) and Mayo (2.7%–2.9%).

¹² The projections in Tables 4.4, 4.5 and 4.6 show the relevant disability rate applied to the child population (aged 3-5) at a county level. In some cases, the data indicate the number of children in a particular county with a disability is small so care should be taken in interpreting the projections in a precise manner.

FIGURE 4.4 **PERCENTAGE OF POPULATION AGED 3-5 YEARS OUT OF TOTAL POPULATION BY COUNTY, 2030 (BASELINE SCENARIO)**



Source: Authors' calculations.
Note: Darker shades represent larger shares of children aged 3-5 years out of total county population.

Tables 4.4 and 4.5 present the results of combining the different projections for children aged 3-5 years in Table 4.3 with the two different estimates of childhood disability obtained from the Census data and the GUI project. Given that we are applying the disability rates uniformly to all counties, the analysis is the same as

that for children aged 3-5 years: counties with the largest populations will tend to have the largest number of children with disabilities, and the counties with the largest shares of children aged 3-5 years out of the total population will also have the largest shares of children with disabilities.

TABLE 4.4 REGIONAL PROJECTIONS FOR CHILDREN AGED 3-5 YEARS WITH DISABILITIES, CENSUS DISABILITY SHARE (4.54%), 2025 AND 2030

	Baseline/Low fertility scenario		High fertility scenario	
	2025	2030	2025	2030
Carlow	102	98	106	106
Cavan	130	121	135	132
Clare	174	168	181	182
Cork	897	849	931	918
Donegal	229	222	238	240
Dublin	2,468	2,210	2,565	2,393
Galway	412	384	429	416
Kerry	210	205	218	221
Kildare	404	378	420	410
Kilkenny	152	144	158	156
Laois	151	140	157	151
Leitrim	47	45	49	49
Limerick	315	300	328	325
Longford	75	72	78	77
Louth	209	196	217	212
Mayo	176	163	183	177
Meath	337	318	350	345
Monaghan	90	83	93	90
Offaly	128	125	133	136
Roscommon	89	87	92	94
Sligo	95	95	99	103
Tipperary	241	229	250	248
Waterford	179	170	186	184
Westmeath	156	148	163	160
Wexford	249	236	259	255
Wicklow	229	219	238	237

Source: Authors' calculations.

TABLE 4.5 REGIONAL PROJECTIONS FOR CHILDREN AGED 3-5 YEARS WITH DISABILITIES, GUI DISABILITY SHARE (8.82%), 2025 AND 2030

	Baseline/Low-fertility scenario		High-fertility scenario	
	2025	2030	2025	2030
Carlow	198	205	191	207
Cavan	253	262	236	255
Clare	338	351	326	353
Cork	1,742	1,810	1,649	1,783
Donegal	445	462	431	466
Dublin	4,795	4,984	4,294	4,650
Galway	801	833	746	808
Kerry	409	424	398	430
Kildare	784	815	735	796
Kilkenny	295	306	279	302
Laois	293	305	271	294
Leitrim	91	95	88	95
Limerick	612	637	583	632
Longford	146	152	139	151
Louth	405	421	380	412
Mayo	343	356	316	343
Meath	655	681	618	670
Monaghan	174	181	161	175
Offaly	248	258	244	264
Roscommon	172	179	169	183
Sligo	186	193	184	200
Tipperary	468	487	444	481
Waterford	348	361	330	357
Westmeath	304	316	288	312
Wexford	484	502	459	496
Wicklow	445	463	425	461

Source: Authors' calculations.

In terms of growth rates, the number of children with disabilities is expected to decrease in all counties between 2016 and 2030, due to the aforementioned decrease in the population of this age range. The smallest fall is expected in Dublin, of between 6 and 13 per cent depending on the scenario. Despite the low fertility rate projected in Dublin, its role as the main destination of international migration, which tends to be of prime working age, mitigates the fall. On the other end of the spectrum, the largest falls between 2016 and 2030 are expected in Monaghan, with between a 37 per cent and 32 per cent fall, and Mayo, with a fall of between 33 and 27 per cent.

4.6 REGIONAL PROJECTIONS MAPPING FUTURE NEED AGAINST CURRENT AIM PROVISION

In this section, we assess the proportion of children with disabilities utilising targeted AIM supports, holding 2019 provision levels constant, under the various population growth scenarios. In Table 4.6, we estimate the lower range for children with disabilities using the CSO-based estimate and applying the lower fertility rate, while the upper range is estimated using the GUI estimate and applying the higher fertility rate.

Given AIM is demand-led and the need for support(s) depends on the difficulties faced by individual children it is extremely difficult to predict how demand may change going forward; as such, we hold the number of AIM places constant, as a baseline at the level of provision in 2019. It is recognised that we make significant assumptions in doing so but this assumption is necessary given the difficulty associated with projecting the demand for the AIM programme. As the number of children with disabilities falls with a declining birth rate this may lead to reduced demand if all types of disability decline at the same rate and if the complexity of disabilities and difficulties remains the same. On the other hand, some types of disability may decline while others, particularly those which need support in educational settings, may increase leading to an increase in the demand for AIM. In particular, it has been well documented that autism spectrum disorders (ASD) have been increasing in Ireland and with that a need for special educational support (Department of Health, 2018). Given these issues with predicting AIM demand we hold AIM provision constant at 2019 levels for the purposes of our projections.

TABLE 4.6 REGIONAL PROJECTIONS FOR AIM COVERAGE FOR CHILDREN AGED 3–5 YEARS WITH DISABILITIES, 2025 AND 2030

County	Current provision AIM places	Current AIM coverage	Projected AIM coverage 2025		Projected AIM coverage 2030	
			Census disability rate and low fertility	GUI disability rate and high fertility	Census disability rate and low fertility	GUI disability rate and high fertility
Carlow	78	42%	53%	37%	55%	37%
Cavan	95	43%	50%	35%	54%	36%
Clare	149	47%	58%	41%	61%	41%
Cork	782	45%	60%	42%	63%	43%
Donegal	182	38%	54%	38%	57%	38%
Dublin	1,320	36%	37%	26%	41%	27%
Galway	259	42%	43%	30%	46%	31%
Kerry	194	53%	63%	44%	65%	44%
Kildare	295	41%	50%	35%	54%	36%
Kilkenny	107	40%	48%	34%	51%	34%
Laois	132	37%	60%	42%	65%	43%
Leitrim	31	41%	45%	31%	47%	32%
Limerick	291	41%	63%	44%	67%	45%
Longford	43	38%	39%	27%	41%	28%
Louth	219	56%	72%	50%	77%	51%
Mayo	158	50%	61%	42%	67%	45%
Meath	297	46%	60%	42%	64%	43%
Monaghan	72	41%	55%	38%	60%	40%
Offaly	135	45%	73%	51%	75%	50%
Roscommon	64	40%	49%	34%	51%	34%
Sligo	54	32%	39%	27%	39%	26%
Tipperary	220	44%	63%	43%	66%	44%
Waterford	132	42%	50%	35%	54%	36%
Westmeath	102	37%	45%	31%	47%	32%
Wexford	176	41%	48%	34%	51%	34%
Wicklow	140	31%	42%	29%	44%	29%
STATE	5,727	41%	49%	34%	53%	36%

Source: Authors' calculations.

Under the low-growth scenario, estimated coverage would rise from 41 per cent in 2019 to 49 per cent in 2025 and 53 per cent in 2030. This is driven by the fact that changes in fertility rates will see the declines in the numbers of children with disabilities nationally over the period from 2019 to 2030. If we take the GUI rate as the base and apply the higher fertility rate, as expected coverage will be lower than under the CSO scenario, but it will still rise over time due to the change in demographics.

4.7 SUMMARY

This chapter presents a brief description of the ESRI regional demographic model methodology and main assumptions. We used this model to generate two scenarios based on different assumptions on the behaviour of fertility and then combined these demographic projections with estimates of child disability to produce estimations of population 3-5 years with disabilities up to 2030 at the regional level. While the largest counties are projected to have the largest number of children with disabilities, out of a share of total population the largest concentration of these children are expected in Longford, Carlow and Westmeath.

Demographic projections do not indicate substantial increases in child disability at a national level; in fact, based on a projection using the CSO incidence and assuming a lower fertility rate, we estimate that AIM coverage based on the current number of places will actually increase from 41 per cent in 2019 to 49 per cent and 53 per cent in 2025 and 2030 respectively. If the level of childhood disability in the 3-5 years age group is closer to the GUI estimate and a higher fertility rate prevails, then AIM coverage based on current provision would stand at 34 per cent and 26 per cent in 2025 and 2030 respectively.

CHAPTER 5

Identifying disability and additional needs among pre-school children using GUI data

This chapter estimates the rate of disabilities and additional needs among young children in Ireland using the *Growing Up in Ireland* (GUI) dataset and shows how these rates differ under different definitions. The GUI provides the most comprehensive nationally representative data on pre-school children in Ireland. A major strength of the GUI survey is that it combines information from both primary caregivers (PCGs) and teachers in capturing disability and difficulty. It also contains a range of measures which could capture special education needs.

Although the Census identifies a range of disability types, we will show how the GUI dataset can highlight additional difficulties, which can help to identify the potential demand for additional supports among pre-school children. This chapter also examines the prevalence of multiple difficulties among children and explores the changes in the rates of different types of disability and additional needs for the same cohort of children at 3 and 5 years.

Drawing from the literature summary in Chapter 1, we argue there is an advantage to using the GUI dataset, in that it relies on information from both PCGs and teachers. It also provides a large, nationally representative sample of pre-school children, which is not available from other sources. Further, the longitudinal aspect of the survey allows us to measure when PCGs recognise disability and difficulty among children, and whether children move out of disability or difficulty categories between 3 and 5 years. Lastly, while there are some overlapping measures of disability or difficulties between the Census and GUI (as outlined in Chapter 2), the GUI also captures relevant difficulties that are not measured or considered explicitly in the Irish Census, such as speech difficulties, which are an important and common form of child disability (Prelock et al., 2008).

5.1 SAMPLE AND DATA

For this analysis, we draw on waves 2 and 3 of the GUI '08 cohort.¹³ These waves were collected when the study children were aged 3 and 5 years, and so they correspond most closely to the cohort of children eligible for the Access and Inclusion Model (AIM) programme. We analyse results from the PCG survey in both waves, as well as results from the survey of teachers regarding study children at age 5. The PCG survey at age 3 was carried out between December 2010 and July

¹³ *Growing Up in Ireland* (GUI) is funded by the Department of Children, Equality, Disability, Integration and Youth (DCEDIY). It is managed by DCEDIY in association with the Central Statistics Office (CSO). Results in this report are based on analyses of data from Research Microdata Files provided by the Central Statistics Office (CSO). Neither the CSO nor DCEDIY take any responsibility for the views expressed or the outputs generated from these analyses.

2011, involving 9,793 observations. Data for the PCG survey at age 5 were collected between March and September 2013, involving 9,001 observations. The teacher survey also took place when the study children were aged 5, between March and September 2013. Importantly, those data were collected before the introduction of the AIM programme in 2016.

We consider five PCG-reported measures of disability and difficulty as they appear in the GUI dataset. These are:

- a disability or a chronic illness that hampers daily activity;
- difficulties with sight;
- difficulties with hearing;
- difficulties with speech; and
- behavioural or emotional difficulties.

We also describe the measures of disability reported by teachers regarding study children at age 5:

- conditions or disabilities that limit the kind or amount of activity the child can do at school; and
- behavioural or emotional difficulties.

We focus on these measures firstly to align with measures of disability recorded in the national Census to provide additional forecasts of demand, and secondly to draw on insights of Banks and McCoy (2011) in assessing needs among school-age children (see also McCoy et al. (2016)).

5.1.1 Definitions

This section presents the definitions of difficulties as they appear in the survey. The data come from the survey of PCGs (at ages 3 and 5), and the survey of teachers (age 5).¹⁴

The first measure is based on the question, asked of PCGs: ‘Does your child have any longstanding illness, condition, or disability?’ PCGs were then asked to select from a set of 21 items, or to note additional conditions or disabilities that were not listed. Importantly, the PCG could choose up to three items to define their child’s disability (see Table A.1 for details).¹⁵ PCGs who recorded any longstanding illness or disability were then asked, ‘Do any of these illnesses hamper [child] in his/her daily activities?’ Where they answered, ‘yes to some extent’ or ‘yes severely’, the

¹⁴ In 99 per cent of cases, the mother is the primary caregiver.

¹⁵ Asthma is the most common longstanding illness recorded. However, because of the way that the data are collected, we cannot say to what extent asthma features as a hampering disability across the whole group. Among those who record only one disability/illness at age 3 (not shown), we find that the highest rates of hampering are for ‘other’ disabilities (32.6% with hampering disability), ‘bone, joint or muscle problems’ (32.1% with hampering disability) and ‘respiratory allergies’ (31.5% with hampering disability). Further, when we look at the composition of those with one hampering illness/disability, in 27% of cases this is asthma.

child was defined as having a hampering disability or illness. This is consistent with the approach taken by Banks and McCoy (2011).

Difficulty with sight (ages 3 and 5) was recorded by PCGs as ‘sight problems requiring correction’. Difficulty with hearing (ages 3 and 5) was recorded by PCGs as ‘hearing problems requiring correction’. We counted only those who have a current difficulty and excluded previous difficulties from our analysis.

In relation to **speech difficulties** the PCG was asked, ‘Do you have any concerns about how (the study child) talks and makes sounds?’ If a PCG chose either the response, ‘yes a little’ or ‘yes a lot’, they were asked follow-up questions on the types of problems encountered; for example, reluctance to speak, speech unclear, speech developing slowly, stammers/stutters, lisp. They were also asked whether the child was receiving treatment for those difficulties. As access to speech and language services can vary regionally and according to PCGs’ means, we include in our definition of speech and language difficulties cases where the PCG is concerned ‘a lot’ about a child’s speech, or if the child is receiving treatment for speech and language difficulties.

The GUI study contains a measure of **socio-emotional and behavioural difficulties** called the Strengths and Difficulties Questionnaire (SDQ) (Goodman, 1997). The scale is composed of five subscales, four of which address difficulties – emotional problems, hyperactivity, peer problems, and conduct problems – and the pro-social scale, which addresses strengths. The four difficulty sub-scales are added together to calculate a total difficulties score. This can be used as a continuous variable or the top decile can be used to identify children with a problematic behavioural score (Goodman, 1997). In a sample of 5-15 year olds, Goodman and colleagues (2000) showed that a total difficulties score at or above the 90th percentile predicted a 15-fold increase in the likelihood of any independently diagnosed psychiatric disorder. The SDQ is completed by the PCG at ages 3 and 5, and by the study children’s teacher at age 5. We focus on the top decile throughout our analysis.

Teacher-reported measures of disability or additional need

We also draw on information provided by teachers about the study children at age 5. Most children (92 per cent) were in school at the time of the teacher survey: of those in school, 30 per cent were in junior infants and 70 per cent were in senior infants. We consider two measures from the teacher survey, which capture a similar range of difficulties to those outlined above: a teacher-rated SDQ score, where a high SDQ rating is one that falls into the top ten percentile of all students, and a general measure of a disability. The latter question asks, ‘Do any of the following limit the kind or amount of activity the Study Child can do at school?’ followed by a list of items. Pupils who have any of the following difficulties are defined as having a teacher-rated disability or difficulty:

- ‘physical disability or visual or hearing impairment’;
- ‘speech impairment’;
- ‘autism spectrum disorder’;
- ‘general learning disability; mild’;
- ‘general learning disability; moderate/severe/profound’;
- ‘specific learning difficulty (e.g. dyslexia)’;
- ‘emotional or behavioural problems (e.g. attention deficit/hyperactivity disorder – ADD, ADHD)’.

Several additional items in the list are excluded from our analysis as they refer to issues arising from the family/social environment or language background.¹⁶ Teachers were also asked ‘Does the Study Child receive special help or resources in the school because of this (these) limitation(s)?’

The average teacher–child ratio is much lower in the school system, at 1:25, than it is in the pre-school system, where there is a limit of 11 children to each pre-school teacher, and the average ratio is 1:9. Therefore, it is likely that some children who were managing without additional assistance in pre-school might struggle in the school setting where there are fewer adults and higher demands for independent self-care. However, the pre-school setting also differs from the home setting; for that reason, teachers’ perceptions of students’ disabilities and their need for additional assistance provide a useful addition to PCG reports.

The teacher reports also ask about a specific set of disabilities, which are closer to those included in the Census than those asked of PCGs. For this reason, the teacher estimates are used as a robustness check for the Census-based projection in Chapter 4.

5.2 ESTIMATES OF DISABILITY/ADDITIONAL NEEDS AMONG CHILDREN AGED 3-5 YEARS

This summary considers a range of possible measures of disabilities, difficulties and limitations, and shows how these measures overlap for children in the survey. It also shows how their permutations lead to different rates of overall disability and difficulty.

5.2.1 Disability or chronic illness that hampers daily activity (PCG data)

PCGs reported that 16 per cent of study children have a longstanding disability or difficulty at age 3 (Table 5.1). This rate increases to 18 per cent once the same children turn 5. Most of these disabilities or illnesses are formally diagnosed, as the

¹⁶ These are: ‘home environment / problems at home’, ‘limited knowledge of the main language of instruction’, ‘discipline problems’ and ‘poor attendance’.

rate of formally diagnosed longstanding illness/disability is on par with the overall rate – 15 per cent at age 3 and 16 per cent when the same children turn 5.

When we consider only disabilities and illnesses that hamper daily activity, we find much lower rates of 5.6 per cent at age 3 and 7.4 per cent at age 5. Given that we are interested in children who are likely to require extra support and that the AIM programme does not require a formal diagnosis to access support, this is our main group of interest. The rate of hampering disability/illness is higher than the rate captured in the Census (shown in Table 2.2).

TABLE 5.1 DISABILITY OR LONG-STANDING ILLNESS

	GUI Wave 2 (age 3)		GUI Wave 3 (age 5)	
	% weighted	N	% weighted	N
Any disability or longstanding illness reported	15.8	1,490	17.9	1,557
Disability/illness that is formally diagnosed	14.8	1,396	16.2	1,425
Disability/Illness that somewhat hampers daily activity	4.6	416	6.1	541
Disability/Illness that severely hampers activity	1.0	87	1.3	95

Sources: GUI '08 cohort, age 3 (wave 2) and age 5 (wave 3) (AMF); teacher survey (RMF).

5.2.2 Sight and hearing difficulties (PCG data)

Regarding sight, we find that 4.6 per cent of children aged 3 have a current difficulty that requires correction. This rate increases to ten per cent when the same children are observed at age 5. A much smaller portion of children are reported to have difficulty with hearing: just two per cent at age 3 and four per cent at age 5.

There is no measure of the severity of these problems; therefore, the rates reported here are much higher than those reported in the Census, where just under one per cent of children reported either of these difficulties (Table 2.2). Once again, it could be that the Census captures a more severe disability tied to sight or hearing, while the measure captured here reflects a difficulty with vision or hearing.

TABLE 5.2 HEARING OR SIGHT DIFFICULTIES, PCG REPORTED

	GUI Wave 2 (age 3)		GUI Wave 3 (age 5)	
	% weighted	N	% weighted	N
Sight difficulty that needs correction (current)	4.6	426	9.8	804
Hearing difficulty that needs correction (current)	2.0	189	3.7	323

Sources: GUI '08 cohort, age 3 (wave 2) and age 5 (wave 3) (AMF); teacher survey (RMF).

5.2.3 Speech problems, PCG reported

Speech and language problems are the most reported difficulty for children at age 3, with just under 20 per cent of PCGs reporting that they have concerns. The measure covers a range of problems including reluctance to speak, stammers, lisps and difficulty finding words. When we restrict the measure to those where the PCG has 'a lot' of concern or the child is receiving treatment, the proportion falls to eight per cent at age 3 and ten per cent at age 5. Importantly, speech difficulties do not feature explicitly in the Census categories of disability (Table 2.2).

TABLE 5.3 DIFFICULTY WITH SPEECH AND HIGH STRENGTH AND HIGH SDQ DIFFICULTY SCORES

	GUI Wave 2 (age 3)		GUI Wave 3 (age 5)	
	% weighted	N	% weighted	N
Speech difficulty: received treatment	6.3	582	9.5	838
Speech difficulty: concerned 'a lot'	4.0	370	3.1	275
Speech difficulty: concerned 'a little'	15.3	1,460	13.4	1,234
Concerned 'a lot' or received treatment	7.6	713	10.1	892
Top decile of the total SDQ difficulties (PCG-rated)	9.2	831	8.8	715

Source: GUI '08 cohort, age 3 (wave 2) and age 5 (wave 3).

5.2.4 Emotional-behavioural difficulties

The final measure is the proportion of children in the top decile of those with emotional or behavioural difficulties, measured using the SDQ (defined in Section 5.2.1). The percentage of children in this category stays the same by definition. However, we will later show that there is movement between children into and out of this difficulty. At ages 3 and 5, we find that nine per cent of children have a top decile score in terms of difficulty (Table 5.3).¹⁷

5.2.5 Teacher-reported disabilities and difficulties

We now turn to disability and difficulty as reported in the teacher survey when the study children were aged 5 years (Table 5.4). We find that 16 per cent of these children have a disability or difficulty that teachers reported limits their activity in school. When we exclude speech impairments and mild general learning disabilities (GLDs) to make the definition more comparable with the Census

¹⁷ Both of our estimates are slightly under ten per cent because there is lumpiness in the distribution of scores, especially in the middle of the distribution.

definition (see Chapter 2), we find that 8.8 per cent of children have a teacher-reported disability.

Teachers identified 7.6 per cent of children as having a speech or language difficulty that limits their activity at school. Given the importance of speech and language for children's development and social participation, it is important to include these issues within a broader definition of additional needs.

Slightly less than ten per cent of children are rated in the top decile of emotional-behavioural difficulties because of clustering within the scores. There is some overlap between the children with limiting conditions and high SDQ score; therefore, when we calculate the proportion with difficulties on either measure we find a total of 20 per cent of children.

Just under ten per cent of children are in receipt of additional school supports for these disabilities or difficulties.

TABLE 5.4 TEACHER-RATED DIFFICULTIES AND DISABILITIES

	GUI Wave 3 (age 5)	
	% weighted	N
Top decile SDQ (teacher-rated)	8.6	702
Child has disability/difficulty that limits child's activity at school	15.6	1,216
Child has any disability/difficulty except difficulties with speech or Mild GLD	8.8	738
Child is in receipt of additional support for any of the disabilities/difficulties	9.2	714
Any teacher reported difficulty (SDQ or limiting disability)	19.8	1,572

Source: GUI '08 cohort, teacher survey (RMF).

5.2.6 Alternative estimates of disabilities and difficulties

Finally, we can consider different estimates of disability and difficulty combining the measures outlined above, similar to the approach used by Banks and McCoy (2011). Table 2.2 in Chapter 2 shows an overall rate of disability of 4.5 per cent, according to Census data. In Table 5.5, we show several different estimates of disability/difficulty applying different definitions, based on the GUI dataset. Each of these measures is higher than the rates in Table 2.2.

At age 3, using the broadest definition – including children with any PCG-reported hampering disability, including issues with sight or hearing, speech issues of concern or requiring treatment and a high SDQ score – we see a rate of 22 per cent. If we exclude issues with sight or hearing where there is no measure of severity, we find a rate of 18.5 per cent.

When we turn to the same children at age 5, data from PCGs, using the broadest definition, the rate increases to almost 30 per cent. However, it drops considerably – to 21 per cent – when we exclude issues of hearing and sight. When we combine reports from PCGs and teachers, and apply the most inclusive definition, which contains a hampering disability, a problem with sight or hearing, a problem with speech, a high SDQ score, a teacher-rated disability or difficulty, the measure captures one-third of children aged 5. If we omit difficulties with hearing or sight from this wider measure of disability, the rate falls to over one-quarter of children aged 5.

All rates are higher than those proposed in previous chapters. This suggests that more sensitive measures of disability or difficulty may pick up more children with a potential need for support at school. Further, each of these rates is similar to those reported by McCoy et al. (2016).

TABLE 5.5 ESTIMATES OF DIFFICULTIES AND DISABILITIES USING DIFFERENT DEFINITIONS

	GUI Wave 2 (age 3)		GUI Wave 3 (age 5)	
	% weighted	N	% weighted	N
Any PCG-reported hampering disability or sight/hearing difficulty or treated speech, concerned speech difficulty or top SDQ score	22.1	2,065	29.4	2,520
Any PCG-reported hampering disability or speech difficulty or top SDQ score (no sight or hearing difficulty)	18.5	1,713	20.9	1,788
Any PCG-reported hampering disability, or sight/hearing difficulty, or speech difficulty, or top SDQ score or teacher-reported disability or difficulty			34.1	2,937
Any PCG- or teacher-reported difficulty excluding sight or hearing			27.1	2,320
Total N		9,793		9,001
Teacher questionnaires completed				8,373

Sources: GUI '08 cohort, age 3 (wave 2) and age 5 (wave 3); PCG survey, teacher survey.

5.3 MULTIPLE DISABILITIES

While the prevalence figures above count children who experience any of the issues described, they do not take account of how these difficulties may accumulate for some children; for example, how some children with hampering disabilities may also have behavioural difficulties. Table 5.6 shows common multiple disability types for children at ages 3 and 5. We also tested whether clusters of disability types could be identified using factor analysis. However, due to the limited overlap between groups, we were not able to draw out satisfactory clusters (results available on request).¹⁸ Our results are similar to those reported

¹⁸ All clusters had eigenvalues (amount of variation explained by a cluster) of less than one.

by Gallagher et al. (2020), who found limited overlap between their disability measures.

TABLE 5.6 INCIDENCE OF MULTIPLE DIFFICULTIES AND DISABILITIES AT AGES 3 AND 5

	PCG-reported, age 3		PCG-reported, age 5		Teacher-reported, age 5	
	% weighted	N	% weighted	N	% weighted	N
No difficulty	77.9	7,728	70.6	6,481	84.5	7,157
1 difficulty	17.3	1,634	22.4	1,932	11.7	906
2 difficulties	3.4	312	4.9	421	2.5	204
3+ difficulties	1.4	119	2.1	167	1.4	106
	100	9,793	100	9,001	100	8,373

Source: GUI '08 cohort, age 3 (wave 2) and age 5 (wave 3); teacher survey.

Notes: Four disability categories were considered for the PCG data at ages 3 and 5: hampering disability, hearing, or sight difficulties, a high SDQ score, difficulties with speech. Disability categories considered in the teacher survey are: physical disability or visual or hearing impairment; speech impairment; ASD; GLD mild; GLD moderate, severe, profound; specific learning difficulties, or emotional or behavioural problems; other limitation to activity; other medical conditions or health problems; or other dyspraxia or motor problems.

Table 5.6 shows that multiple disabilities are uncommon. Across all three sources, it is most common for just one disability or difficulty to be recorded for each child. A minority list two or more measures at every age, even when we consider the teacher data at age 5. Due to this small overlap, it is not possible to produce common clusters of disabilities for our analysis.¹⁹ This stems from the limited overlap and the low correlation between disability types, which leads to clusters with low eigenvalues. Some of the most common overlapping categories are listed in Table 5.7 below. They show that none of the clusters rises above one per cent of the sample and that speech problems and a high SDQ score are the most common cluster for children aged 3, while hearing or sight and speech issues are the most common cluster for children aged 5.

¹⁹ Beyond running a factor analysis, we explored principle component analysis and a polychoric factor analysis, specifically designed for binary outcomes. Each of these approaches produced similar results with low eigenvalues. The results are not reported here but are available on request.

TABLE 5.7 MOST COMMON COMBINATIONS OF DISABILITIES OR DIFFICULTIES (UNWEIGHTED)

	Age 3		Age 5	
	%	N	%	N
Any hampering disability and speech problem	0.5	49	0.8	74
Any hampering disability and in top decile SDQ	0.4	44	0.8	74
Any hampering disability and hearing or sight	0.5	49	0.6	56
Hearing or sight, and speech	0.6	62	0.9	83
Hearing or sight and SDQ	0.5	47	0.9	81
Speech problem and SDQ	0.7	66	0.6	53
Total experiencing 2 disabilities	3.2	312	4.7	421

Source: GUI '08 cohort, age 3 (wave 2) and age 5 (wave 3).

Note: Four categories of disabilities were considered: hampering disability, hearing, or sight issues, a high SDQ score, difficulties with speech.

In general, we see that multiple disability types, using the measures considered here, are uncommon. Although Chapter 2 notes some overlap between measures in the Census, our measures do not capture the same degree of overlap. Specifically, we use a different set of indicators to the Census. Our measure of hampering disability is likely to disguise some cases of multiple disability which, due to the way in which the survey was designed, cannot be separated.²⁰

5.4 DISABILITIES AND DIFFICULTIES OVER TIME

As the data concern the same children at ages 3 and 5, we can examine the extent to which difficulties appear at each age, which difficulties decline between age 3 and age 5 and which difficulties emerge over time. We can capture the types of difficulties that remain persistent between 3 and 5 years. This longitudinal analysis is confined to the PCG data, as they were interviewed for both waves of the survey.

The majority of children (90 per cent) do not experience hampering disabilities/illnesses at either 3 or 5 years. A small group of children have a hampering disability at age 3, but this is not recorded by their PCG at age 5 (three per cent). This may happen because a chronic illness has been successfully treated or because the illness or disability no longer limits the child's activities because of other interventions or coping strategies. A slightly larger group of children (just under five per cent) have a hampering disability at age 5 that was not recorded by their PCG at age 3. In some cases, this may be due to the onset of a condition, while in others a pre-existing condition may only have become apparent when the child began attending pre-school or school. This is particularly likely with learning disabilities, which have been shown to increase in prevalence from birth and peak

²⁰ If we drop the requirement of an illness or disability being hampering, a total of 5.4 per cent of PCGs report their child as having two or more longstanding illnesses/disabilities at 5 years, but this is likely to include many mild conditions.

at age 12 (Watson and Nolan, 2010). Finally, a minority of children – just over two per cent – have a hampering disability at both 3 and 5 years.

In the case of speech and language difficulties, three per cent of children were reported as having difficulty at age 3 but not at age 5. A larger portion – six per cent – were reported as having a difficulty at age 5 but not at age 3, suggesting that for many affected children, these issues are not picked up until after 3 years. Almost four per cent of children have persistent speech difficulties at ages 3 and 5.

Similarly, in the case of sight and hearing difficulties, we find a significant increase in the identification of such issues at age 5 compared to age 3. For almost nine per cent of children, a hearing or sight problem becomes apparent to their PCG when they are aged between 3 and 5 years. As before, this is likely to partly reflect the fact that as the children grow older, they become more involved in activities outside of their immediate family and home. About two per cent of children are reported to have such difficulties at age 3 but not at age 5. A slightly larger portion – four per cent – have these difficulties at both ages 3 and 5.

In the measures discussed so far, the number of difficulties reported at age 3 and aged 5 is roughly equal. If we take the number of children experiencing difficulty at 3 years but not 5 years together with the number of children experiencing issues at both 3 and 5 years, we see that PCGs' tendency to notice disabilities and difficulties is roughly equal at both ages.

TABLE 5.8 DIFFICULTIES AND DISABILITIES OVER TIME

	No difficulty at age 3 or 5	Difficulty at age 3, none at 5	Difficulty at age 5, none at 3	Difficulty at both age 3 and 5
Hampering disability (%)	89.8	2.9	4.9	2.4
Hampering disability (N)	7,855	238	410	196
Speech issues (%)	86.5	3.4	6.3	3.8
Speech issues (N)	8,818	372	551	341
Sight issues (%)	88.8	1.3	6.7	3.2
Sight issues N	7,804	118	523	255
Hearing (%)	94.9	1.4	3.0	0.6
Hearing (N)	8,274	115	257	54
Hearing <u>or</u> sight (%)	85.3	2.2	8.7	3.8
Hearing <u>or</u> sight (N)	8,751	275	747	309
Top SDQ score (%)	85.5	5.8	5.6	3.1
Top SDQ score (N)	7,557	462	442	240
Total disability/ difficulty measures (%)	62.3	8.3	16.5	12.9
Total disability/ difficulty measures (N)	6,587	975	1,430	1,090

Source: GUI '08 cohort, age 3 (wave 2) and age 5 (wave 3) (AMF).

Regarding the SDQ score, a substantial level of change is found again for individual children between the ages of 3 and 5 years. Only three per cent of children are in the top decile of the difficulties score at both ages. About six per cent of children were in the top SDQ at age 3 but were no longer in the difficulty range at age 5 (meaning that two-thirds of the original 'difficulty' group are no longer in that category). A similar percentage of children were in the top decile at age 5 but not at age 3. It is likely that the group with persistent difficulties are most likely to need additional supports.

Taking all measures of disability/difficulty, we see that eight per cent of children exit the group needing special support and assistance, but that a core group remain in difficulty at both ages 3 and 5 (12.9 per cent of all children). A third group emerges comprising those who were not identified as having an additional need for support at age 3, but who moved into a category potentially requiring support by age 5 (16.5 per cent).

5.5 SUMMARY

There are challenges to measuring disability and difficulty among children, something that is widely noted in the literature. This chapter outlines the prevalence of disability and difficulty for children aged between 3 and 5 years as estimated from the GUI dataset, using a variety of measures that have been adopted in previous surveys and studies. These measures produce a wide range of estimates that are higher than the disability rates identified in the Census, even when similar categories are used in the analysis. The higher rates emerge in both the PCG survey and the teacher survey. The output suggests there may be a higher rate of difficulty among young children than that captured by the Census.

The most conservative estimate of disability and difficulty comes from the teacher reports regarding children at 5 years. Using a definition that is aligned as closely as possible with the Census measure, this teacher-reported rate comes in at 8.8 per cent; this was used in the population projections as a robustness check.

The PCG-based estimates, which involved a definition that includes hampering disability, high SDQ score or speech difficulty, produce a rate of 18 per cent at age 3 and 21 per cent at age 5. The broadest definition of disability and difficulty includes assessments from both PCGs and teachers at age 5 and includes sight or hearing difficulties, speech difficulties, high SDQ scores and any teacher-related disability or difficulty. Under this definition, over 33 per cent of children experience some difficulty. The analysis also finds that a much smaller proportion of children experience multiple difficulties and that early childhood is a period in which difficulties emerge and recede.

The analysis underlines the complexity in assessing the level of need for additional supports among young children at an aggregate level. The prevalence of difficulties varies with the social context (home, school, pre-school), the age of the child, the informant (PCG or teacher), as well as the definitions used. Even the lowest estimates suggest there may be considerable need for supports for pre-school children to fully benefit from early years education.

The GUI children were the first cohort to benefit from the Early Childhood Care and Education (ECCE) scheme, with 96 per cent of the participating families taking up this opportunity. However, their participation preceded the introduction of the AIM programme, which is demand driven rather than based on a predetermined resource allocation system in which applications can be lodged at any time. This flexibility means that the system can respond to needs as they arise and become apparent to PCGs and educators at different ages and in different social contexts. Given the varied and changing nature of children's needs, this is a valuable feature of the system.

Further longitudinal analysis of the association between these different measures and subsequent child outcomes (cognitive, educational, social and health) could be usefully undertaken with a view to identifying which measures best predict poor outcomes.²¹ This information could then be used to tailor supports for the current cohorts of pre-school children within the approach of progressive universalism which underpins the AIM programme.

²¹ There is now information available on how the '08 cohort of children are faring across all these domains (cognitive, educational, social and health) at age 9.

CHAPTER 6

Summary and conclusions

6.1 INTRODUCTION

Access to early years provision is now widely recognised, across all strands of academic literature, as being a major factor in determining individual human capital development. However, children with disabilities will experience substantial barriers in accessing, and fully benefiting from, early years interventions. In order to inform policy in this area, this study assesses the incidence of childhood disability rates in Ireland among children eligible for early years education and care.

This study examines the prevalence of childhood disability in the context of the supports provided through the Access and Inclusion Model (AIM) programme. AIM is the main initiative in Ireland designed to facilitate children with disabilities accessing mainstream early years education and care provision for pre-school children. Ireland, in line with most other developed countries, has extended early years education and care access substantially over recent times. All eligible children can benefit from free early childhood care and education for two years before they start primary school under the Early Childhood Care and Education (ECCE) programme. In order to support children with a disability to access the ‘free preschool’ initiative, the AIM programme of supports was introduced in 2016.

Measurement of the prevalence of disability among children in the population is a difficult task as the conceptualisation of disability is multifaceted and has evolved over time. Different datasets typically adopt different classifications of disabilities. This study firstly draws on the categories of self-reported disabilities available from the Census of Population in the years of 2011 and 2016 to document the disability rates among children aged 3-5 years. This age cohort was chosen as they align most closely with the ages when children access early years education. The level of childhood disability is assessed both at a national and a county level using various measurement approaches. GUI data are used to further explore the prevalence of disability and difficulty for children aged between 3 and 5 and the extent to which children experience multiple difficulties. By superimposing the data from the Programmes Implementation Platform (PIP) on regional AIM provision levels, we provide further insights into the extent to which disparities exist between the potential need and current levels of support.

The recently developed ESRI regional demographic model is used to examine the projected evolution of need at a county level over a ten-year period, under various

measurement approaches and assumptions regarding the fertility rate, to inform the policy planning process going forward.

6.2 MAIN FINDINGS

Based on the Census of Population data, 4.25 per cent of those aged 3-5 years had a disability in 2011, with the figure rising to 4.54 per cent in 2016. This represents an increase in the disability rate among 3-5 year olds of approximately 6.69 per cent over the 2011 to 2016 period. In terms of the distinguishable disability types, intellectual disabilities were the most dominant in 2011, at 2.06 per cent, followed by physical disabilities at 1.71 per cent. The incidence of 3-5 year olds with blindness/deafness and psychological/emotional disabilities was approximately 0.54 per cent and 0.59 per cent respectively in 2011. However, in the same year, the largest single category of disability among children aged 3-5 years were recorded in the 'other' category, at 2.76 per cent; this grouping incorporates rather broad responses related to (i) other disabilities including chronic illness and (ii) difficulties participating in other activities.

While the increase in the total disability rate among 3-5 year olds between 2011 and 2016 was 6.69 per cent, a more substantial range of variations were observed in the incidences of individual forms of disability. For example, between 2016 and 2019 the proportion of those reporting as 'other' increased by 4.58 per cent while the proportion of children aged 3-5 years with psychological/emotional conditions increased by 68.45 per cent.

In 2011, the regional incidence of disability by county for 3-5 year olds ranged from 3.25 per cent in Monaghan to 5.40 per cent in Limerick, compared to a national average of 4.25 per cent. In 2016, the incidence of disability ranged from 3.59 per cent in Leitrim to 5.81 per cent in Offaly, compared to a national average of 4.54 per cent. Over both time periods, the incidence of childhood disability was consistently higher than expected in Offaly and Limerick, given the share of children with disabilities there, and consistently lower than expected in Leitrim and Clare.

The comparable GUI estimate of childhood disability overall is 8.82 per cent compared to the total childhood disability rate estimate from the Census (2016) of 4.54 per cent. This indicates a factor increase of approximately 1.9 times greater. The categories examining blindness, deafness and difficulties with physical activities closely align across the two estimates, at approximately three per cent. The GUI estimates for intellectual disability, difficulty with learning, remembering or concentrating, and psychological or emotional conditions are higher than the Census estimates. Conversely, as discussed above, the higher 'other' rate in the Census data is significantly greater than the 'other' categories recorded in the GUI teacher assessments, due to the fact that the GUI questions focusing on disability

and other difficulties are more extensive than the two questions included in the Census of Population.

The number of AIM-supported children in proportion to the number of children with disabilities increased considerably between 2016 and 2019. Participation in AIM is voluntary and relies on an application being made to Pobal/Better Start, so we would never expect to see 100 per cent of children with disabilities utilising the programme. Moreover, there no clear sense of what the most appropriate rate of utilisation is for such a programme. However, in 2016 the number of AIM-supported children in each county equated to between 10 and 20 per cent of the estimated number of children with disabilities aged 3-5 years, based on data from the Central Statistics Office (CSO). In 2019, the situation appears to have fundamentally changed, with the vast majority of counties having a proportion of children with disabilities benefiting from targeted AIM supports of between 40 and 60 per cent.²² This indicates a rapid expansion of both up-take over the period from the launch of the programmes in 2016 up to 2019. Coverage in all counties increased in that period but to differing degrees. Specifically, the counties with the lowest coverage in 2016 had increased the most by 2019.

While we do not know the appropriate proportion of AIM-supported children relative to the population of children with disabilities, we can ask questions as to why it varies so considerably across the country. Due to the nature of the programme, some supports, such as staff training, would take time to implement, which may partly explain the large increase between 2016 and 2019. Furthermore, given the fact that beneficiaries must apply for access to the programme, awareness of its available interventions, among both primary caregivers (PCGs) and providers, plays a key role as regards to availing of supports and this is likely to have increased over time. Perhaps some counties provided better information on the AIM programme or have local groups supporting families with children with disabilities who were better positioned to advise people on the programme than others. Alternatively, it could be that differing levels of the various types of disability has an impact. The proportion of children with disabilities benefiting from targeted AIM supports at a county level is positively correlated with the county's rate of physical and intellectual disabilities, which may suggest that receiving support from the programme is better suited to these types of disability or that these types are more in need of support in accessing ECCE than others. On the other hand, the large variation between counties in terms of the proportion of children receiving support may reflect unmet need in some counties if we assume that the ratio of support needs to disability prevalence is constant across the country.

²² However, it needs to be reiterated that this is based on 2016 Census figures for the number of children with disabilities.

Demographic projections do not indicate substantial increases in child disability at a national level. In terms of projected growth rates, the number of children with disabilities is expected to decrease in all counties between 2016 and 2030, due to the aforementioned decrease in the population within this age range. Based on projections using the CSO disability incidence and assuming the lower baseline fertility rates, we estimate that the proportion of children with disabilities benefiting from targeted AIM supports, based on the current number of children availing of these targeted supports, will actually increase from 41 per cent in 2019 to 49 per cent and 53 per cent in 2025 and 2030 respectively.^{23,24}

The prevalence of disability and difficulties for children aged 3-5 years, as estimated from the GUI survey, is higher than the disability rates noted in the Census, even when similar categories are used in the analysis. The higher rates emerge in both the PCG and teacher surveys. The output suggests there may be a greater level of need for additional supports for young children than that suggested by the Census findings. Moreover, while the prevalence estimates document a count of children who experience any of the issues described, they do not take account of how these difficulties may accumulate for some children; for example, some children with hampering disabilities may also have behavioural difficulties. However, our results exploring how common multiple disability types for children at 3 and 5 years are similar to those reported by Gallagher et al. (2020), who found limited overlap between their disability measures.

6.3 IMPLICATIONS FOR POLICY AND PRACTICE

The difficulties involved in measuring the level of disability and additional needs among children are widely noted across the literature. Research on the prevalence of childhood disability and the circumstances and characteristics of children with disabilities is crucial for public policy development in order to provide appropriate and timely service provision.

Disability is a multifaceted concept that has evolved over time. Once thought of as a purely medical problem for an individual, disability is now deemed a social construct. While the prevalence estimates here detail a count of children who are recorded, across differing datasets, as having disabilities or experiencing disabilities to varying levels, they do not take account of the range and specific types of supports required to support children with disabilities in early years education and care. In this context, the AIM programme occupies a distinctive position in the landscape of early years disability supports, characterised by its

²³ In the 'baseline' scenario, the overall total fertility rate (TFR) is assumed to decrease from 1.8 in 2016 to 1.6 in 2031 and remain constant thereafter.

²⁴ This is based on the assumption that the number of AIM-supported children remains the same.

child-centred approach, and its focus on facilitating children with disabilities to participate more fully in pre-school alongside their peers.

While demographic projections do not indicate substantial increases in child disability at a national level, there are seven levels of support provided by the AIM programme, which range from universal to more targeted approaches depending on the needs of the child and their pre-school setting. Different needs arise and become apparent to PCGs and educators at different ages and in different social contexts. For this reason, considerable flexibility is required of the system of supports in place, so that it may recognise and adapt to both the changing nature and complexity of needs.

Access to education in children's early years has been well documented as an important factor in long-term development (Barnardos, 2016). This is particularly important for children with disabilities, as they typically have lower levels of educational attainment than children without a disability (Disability Federation of Ireland, 2017). It also has far-reaching benefits for society as a whole (OECD, 2006). Early years education provision supports the labour force participation of women and assists the integration of immigrants with young children (OECD, 2006).

The proportion of children with disabilities who were supported by the AIM programme increased considerably between 2016 and 2019. This is not surprising, given the nature of the programme, the length of time required to raise awareness of it among eligible families and the time required to utilise some supports, such as training for the ECCE providers. We do not know the ideal proportion of children with disabilities to benefit from such a programme, but questions arise related to the large county-level differences observed across the country. In 2019, 79 per cent of children with disabilities in Louth were being supported by AIM, compared to only 49 per cent in Sligo. Such discrepancies may point to there being a level of unmet need among children with disabilities in some counties. It is imperative that PCGs and ECCE providers are adequately informed about the programme across all areas. Connecting with groups who support families with children with disabilities or other key stakeholders engaging with these families may help in ensuring that all those who may be eligible are aware of the programme. On the other hand, we find that childhood disability is not geographically neutral. It may therefore be the case that types of disability and, perhaps more importantly, complexity of the disabilities and difficulties faced differ at a county level, which would impact the demand for AIM supports. For some children the universal supports provided by AIM may be enough to fully support their inclusion in ECCE. More research is therefore required to determine if this is a factor in the wide variation of AIM utilisation across the country.

It is likely that the programmes reach will continue to grow organically as more children utilise the supports and benefit from the programme. The data used here

to measure the number of unique AIM-supported children by county relate to 2016, the year the programme was introduced, and 2019. As it may still be relatively early in terms of roll-out of such a programme, it would be useful to update these findings, so that we could assess whether the number of AIM-supported children continued to increase after 2019 or whether it started to plateau. There is also evidence of a strong correlation between age and disability for children, particularly with a significant increase in reporting of disability between 3 years and 5 years.²⁵ This suggests that early years education has an important role to play in identifying difficulties children may be facing. This further emphasises the importance of having all children fully supported in accessing ECCE.

²⁵ Reported disability increases significantly between ages 3 and 5 and while many of these will have been pre-existing they are more likely to be identified or diagnosed when children enter education.

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APPENDIX I

TABLE A.1 PREVALENCE OF LONGSTANDING CONDITIONS AT AGE 3 AND AGE 5

	Age 3		Age 5	
	N	%	N	%
Asthma	580	6.2	689	8.2
Cystic fibrosis	-	-	-	-
Heart abnormalities	88	1	64	0.9
Eczema or skin allergy	418	4.3	349	3.8
Respiratory allergy	105	1.3	126	1.5
Food and digestive allergy	151	1.5	165	1.8
Non-food allergies	37	0.4	56	0.7
Bone joint or muscle problems	67	0.7	87	1
Problems using arms or legs	36	0.4	35	0.4
Problems using hands or fingers	-	-	-	-
Hyperactivity or problems with attention	-	-	32	0.5
Severe behavioural problems	-	-	-	-
Diabetes	-	-	-	-
Kidney problems	51	0.5	39	0.4
Migrainous headaches	-	-	-	-
Epilepsy or seizures	38	0.4	34	0.4
Down syndrome	-	-	-	-
Spina bifida or hydrocephalis	-	-	-	-
Cerebral palsy	-	-	-	-
Autism spectrum disorder	39	0.4	95	1.1
Other longstanding illness or condition or disability	65	0.7	62	0.8
Other ear problems excluding hearing	32	0.3	31	0.5
Other problems with tonsils or adenoids	30	0.3	-	-
Other eye problems	-	-	-	-
Other speech language or hearing problems	-	-	49	0.6
Other congenital and genetic disorders not specified elsewhere	35	0.4	80	1.3
Other gastric and bowel problems	71	0.8	48	0.6
Other chest lung and breathing problems	-	-	-	-

Source: GUI '08 cohort, age 3 (wave 2) and age 5 (wave 3). Weighted by cross-sectional weights.

Note: Cells with less than 30 cases cannot be reported and are represented by '-'.

TABLE A.2 MATRIX OF TYPES OF DISABILITIES RECORDED ACROSS CENSUS AND GUI

	Census of Population (2016) (Age 3-5)	GUI PCG Age 3	GUI PCG Age 5	GUI Teacher (Age 5)
Blindness or vision impairment	Blindness or deafness 0.64%	Sight difficulty 4.6%	Sight difficulty 9.8%	Physical disability, visual or hearing impairment 3.2% (267)
Deafness or a serious hearing impairment		Hearing difficulty 2%	Hearing difficulty 3.7%	
A difficulty with basic physical activities	Physical 2.25%	Hampering disability 5.6%	Hampering disability 7.4%	
An intellectual disability	Intellectual 2.62%			
A difficulty with learning, remembering or concentrating		High total SDQ (9.2%)	High total SDQ (8.8%)	ASD 1.39% (116) General learning disability, mild 2.94% (246) General learning Disability: Moderate, Severe, Profound 0.85% (71) Specific learning difficulty e.g. dyslexia 0.99% (82)
A psychological or emotional condition	Psychological /emotional 0.99%	High total SDQ (9.2%)	High total SDQ (8.8%)	Emotional or behavioural ADD ADHD 2.64% (221)
Other disability, including chronic illness	Other 2.89%			Other limitation to activity 0.85% (71) Other limiting medical or health problem 0.61% (51) Other motor skills, dyspraxia 0.43% (35)
Speech problems		Speech difficulty (7.6%)	Speech difficulty (10.1%)	Speech difficulty 7.63% (639)
Total	Any disability 4.54% (9,587)	Any of above 22.1% (2,166)	Any of above 29.4% (2,646)	Any of above 15.55% (1,301)
Total excluding difficulties with hearing/sight		Any of above, drop hearing and sight difficulties 18.5% (1,810)	Any of above, without hearing and sight difficulties 20.9% (1,879)	
Total excluding speech issues	Any disability 4.54% (9,587)			Any of above, minus speech or mild GLD 8.82% (738)

Source: Census 2016 and GUI, '08 cohort, age 3 (wave 2) and age 5 (wave 3).

Notes: This matrix presents a set of disability and difficulty rates found in the Census (2016), and the GUI's infant cohort wave 2 and wave 3, as well as the teacher survey at age 5. Detailed definitions of specific rates can be found in Section 5.211. Regarding the primary caregiver surveys (PCG) at ages 3 and 5 (columns 3 and 4), a sight difficulty or a hearing difficulty refers to a current difficulty as recorded in the survey; a hampering disability refers to a disability that somewhat or severely hampers daily life; a high SDQ score is one that falls into the top decile of the distribution; a speech difficulty is an instance where PCGs are concerned 'a lot' about speech or an instance where children are receiving treatment for speech and language difficulties. GUI data are weighted using appropriate survey weights.

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