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Children with Disabilities and Long-term Conditions



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Introduction

There are many dimensions of health, both mental and physical, including disabilities, short-term illness, milder longer-term conditions and short-term injuries. This broad spectrum of conditions means care must be taken when considering numbers affected by health issues and in associating these numbers with results identified in the literature. Throughout, as far as possible, the focus is on those who are disabled and/or experience limiting long-standing health conditions (LLSCs).

Children with disabilities

The Equality Act 2010 defines a person as disabled if they have a physical or mental impairment that has a ‘substantial’ and ‘long-term’ negative effect on their ability to do normal day-to-day activities. Under the Act, ‘substantial’ means more than minor or trivial, and ‘long-term’ is defined as 12 months or longer.¹

Children and young people with disabilities are a particularly vulnerable group in society. To reach their potential to make a positive contribution to society, children and young people with disabilities and their families need effective support from statutory health, education, social care and voluntary services at the appropriate stages of their lives. Current financial pressures and national policies call for a more integrated, joint agency approach to ensure the best use of resources in commissioning these services.

The needs of disabled children, young people, and their families are unique to them, often complex, and change over time. The challenge is to understand these needs and develop a system around them that is flexible enough to meet the needs of the person and their families. Some will have highly complex needs requiring multi-agency support across health, social services, and education – the most extreme example perhaps being those who are technology-dependent. Other children will require substantially less support, although nevertheless have a long-term disability.

Disabled children and young people are at greater risk of underachieving, are often excluded from the opportunities available to their non-disabled peers, and can experience greater poverty. These circumstances can lead to poor physical and mental health outcomes.

Children with disabilities in Blackpool

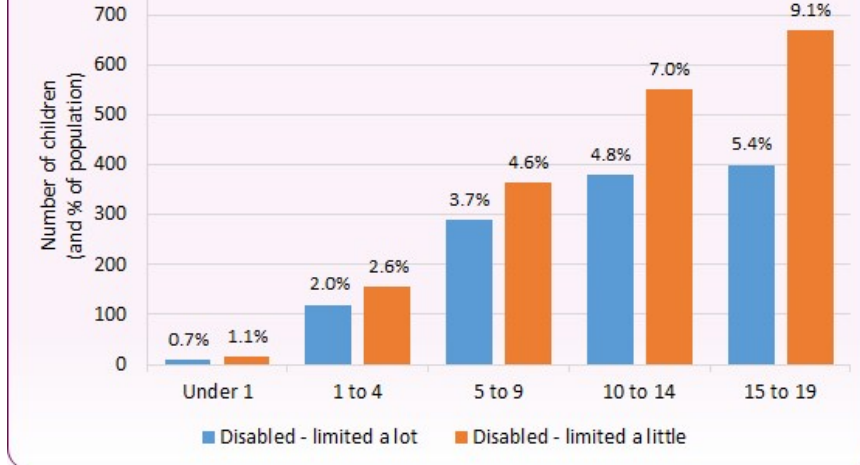
Office for National Statistics (ONS) data from the 2021 Census identified 2,955 children and young people under the age of 20 in Blackpool who would be considered disabled under the Equality Act 2010 definition. This equates to 9.8% of the Blackpool 0 to 19 population (compared to 7.3% across England):

- 3.9% of the Blackpool 0 to 19 population are considered to be disabled with day-to-day activities limited a lot (Eng 2.8%)
- 5.8% are disabled with day-to-day activities limited a little (Eng 4.5%)
- Approximately 57% of disabled children and young people in Blackpool are male
- The proportion of the Blackpool population who are considered disabled by age group increases from 1.8% among those under one year old to 14.5% of 15 to 19 year olds ([figure 1](#))
- The proportion of disabled children aged 1 to 4 years in Blackpool is the fifth highest among English local authorities (4.6% compared to 3.0% across England)

Figure 1: children with disabilities in Blackpool, Census 2021 (numbers and age group proportion by level of disability)

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Source: Office for National Statistics (ONS), Census 2021

Long-term conditions: diabetes, asthma and epilepsy

Long-term conditions in children can manifest in a variety of ways, but this section will focus primarily on childhood diabetes (type 1), asthma and epilepsy. Providing effective care for these conditions will lead to better patient care and a reduction in preventable emergency admissions, which are costly and expose patients to otherwise avoidable clinical risks such as healthcare associated infections. The importance of reducing emergency admissions is recognised by the inclusion of an indicator measuring this patient outcome in the quality premium, the better care fund, and in the [NHS Outcomes Framework](#) - unplanned hospital admissions for diabetes, epilepsy and asthma (under-19s).²

Diabetes

Type 1 diabetes is an autoimmune condition resulting in 'insulin dependence' as the person's pancreas fails to produce any insulin to control blood glucose levels, and therefore requires insulin injections for life. With type 2 diabetes, insulin does not work properly or there is not enough of it.

- In 2023/24, there were an 33,437 children and young people aged under 19 in England with diabetes. The majority (93.3%) of these children have type 1 diabetes; 1,337 had type 2.³
- 94% of children and young people with type 2 diabetes had a BMI in the overweight or obese range, compared to 42% with type 1 diabetes.⁴

Asthma

Asthma is a long-term condition which causes breathlessness, wheezing and coughing. The severity of the symptoms varies from person to person from mild to severe. Triggers include smoking, pollen, damp housing, cold air and exercise. For children diagnosed with asthma, the condition may disappear or improve during the teenage years, although it can return later in life. Moderate or severe childhood asthma is more likely to persist or return later on. The UK has one of the highest prevalence, emergency admissions and death rates for childhood asthma in Europe.

- Around **1 in 11 children and young people in the UK** are estimated to be living with asthma, and around 1 million children are receiving treatment for the condition.

Epilepsy

Epilepsy is a condition diagnosed in those who have had more than one epileptic seizure. An epileptic seizure is when a sudden burst of electrical energy in the brain causes a temporary sensory overload in the brain.

- Approximately 112,000 children and young people aged 0-24-years in the UK have a diagnosis of epilepsy along with a current prescription of anti-epileptic drugs. For those under-19 years, this is estimated at 63,400.⁵

Facts, figures and trends

Based on national proportions and estimates:

- The number of children aged under 19 with type 1 diabetes in Blackpool is 158.⁶
- There are an estimated 2,759 children and young people aged under 19 living with doctor-diagnosed asthma in Blackpool.⁷
- Blackpool has an estimated 138 children aged under 19 with diagnosed epilepsy.⁸

Note: given the potential influences of deprivation, poor quality housing, and rising obesity levels, Blackpool levels may be higher than these estimates.

Nationally, asthma, diabetes and epilepsy account for approximately 94% of emergency hospital admissions for children (under 19 years) with long-term conditions.⁹

Between 2013/2014 and 2022/2023 national rates for 0-19 emergency admissions for asthma and epilepsy have decreased and are improving, although for diabetes the trend shows it rates are increasing and getting worse.

The coronavirus pandemic (COVID-19) impacted on hospital admissions and hospital admission data from late 2019/20, continuing into 2020/21, with fewer patients being admitted to hospital over this period. Both national and local data (see below) suggests that this mostly affected asthma admissions. This may be due to a combination of a) reduced presentation of asthma patients to hospital (and increased self-management) due to the associated respiratory risks of COVID-19, b) asthma sufferers being admitted with COVID-19 related symptoms (rather than asthma as their main diagnosis), and c) reduced air pollution and transmission of other respiratory viruses, including influenza, during lockdown periods.¹⁰

Among under-19s in Blackpool:

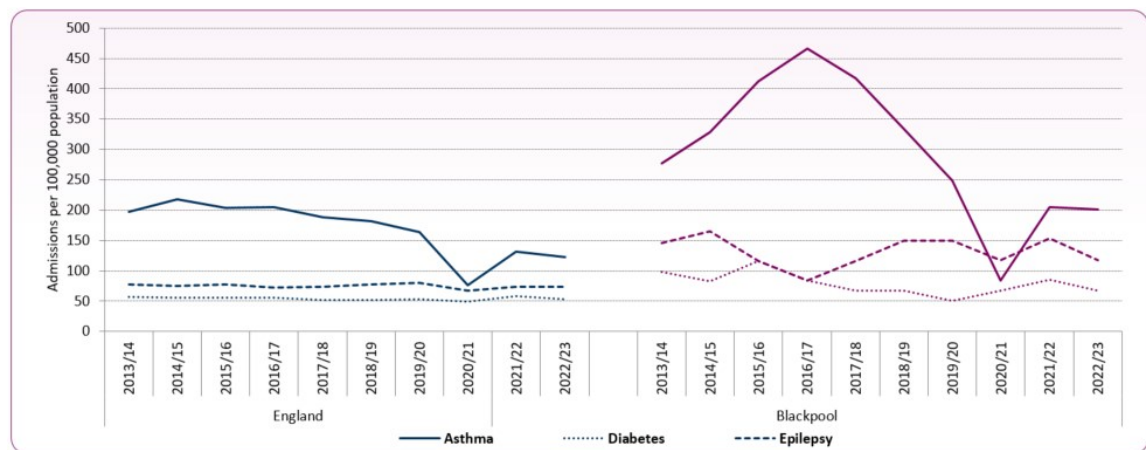
- There were approximately 60 unplanned admissions for asthma in 2022/23, compared to 125 in 2017/18. In COVID-19 affected 2020/21 there were 25 admissions.
- There were approximately 35 unplanned admissions for epilepsy in 2022/23, the same as in 2017/18 and in COVID-19-affected 2020/21.
- There were approximately 20 unplanned admissions for diabetes in 2022/23, the same as in 2017/18 and in COVID-19-affected 2020/21.

Note: above data is rounded to nearest 5 (hence approximate values)

In non-COVID-19 pandemic affected years, asthma accounted for more than half (60%) of the emergency admissions for these three conditions, epilepsy for 25% and diabetes for 15% in Blackpool.

Figure 2 shows the trend for asthma, diabetes and epilepsy emergency admission rates for Blackpool and England. Admission rates for asthma fell from a high of 466 per 100,000 in 2016/17 to 333 per 100,000 in 2018/19, reducing to 84 per 100,000 in 2020/21, with the rate for 2022/23 at 201. Rates for both diabetes and epilepsy fluctuated between 2013/14 and 2018/19 (being sensitive to relatively small numbers), with the rates of both rising slightly in 2021/22 before reducing in 2022/23.

Figure 2: Emergency (unplanned) hospitalisations for asthma, diabetes and epilepsy in under 19s, crude rate per 100,000 population: Blackpool and England 2013/14 to 2022/23



Source: OHID, Child and Maternal Health Profiles / NHS Digital, Hospital Episode Statistics, 2020/21. Note: Due to relatively small numbers, confidence intervals for Blackpool rates may be large.

Whilst Blackpool admission rates for epilepsy among children aged 10 to 18 have been similar to the national average since 2018/19, admissions for children aged 0 to 9 have been significantly higher, with a 2022/23 rate of 163.0 per 100,000, compared to 92.9 for England.

Pre-COVID, emergency admission rates related to asthma among both 0 to 9s and 10 to 18s were significantly higher than the England rate, though COVID-19 affected 2020/21 saw both rates fall to a level similar to the national average. In both age groups for Blackpool (260.9 per 100,000 for 0-9-years, and 138.1 per 100 for 10-18-years) the rate is significantly higher compared to England (154.7 per 100,000 for 0-9-years, and 88.2 for 10-18-years).

Risks and contributory factors

The prevalence and severity of some long-term conditions can be influenced by a range of wider conditions. Long-term conditions can also impact on other outcomes (for example in relation to education):

- There is an increased prevalence of children with long-term conditions in areas of high deprivation (particularly asthma).¹¹
- There is a significant relationship between deprivation and child emergency hospital admissions for both asthma and epilepsy across England: as deprivation increases, admission rates increase.
- Children and young people who have a long-term condition can be at risk of missing out on educational opportunities due to prolonged absences from school, from ill health or multiple appointments.
- In early childhood, asthma is more common in boys than in girls.¹²
- There are increased risks for asthma, asthma development, wheezing and respiratory infections for people living in damp houses and Blackpool has high levels of substandard housing in poor repair.¹³
- Concerning trends have been identified in prevalence of obesity in children with type1 diabetes as they reach adolescence.¹⁴
- Blackpool has significantly higher proportions of children who are **overweight or obese** than the national average

National and local strategies

- NICE guidance on **Diabetes** covers the diagnosis and management of type 1 and type 2 diabetes in children and young people aged under 18.
- NICE guidance on **Asthma** covers the diagnosis and treatment of asthma in adults, young people and children aged 12 months and older.
- NICE guidance on **Epilepsy** covers the diagnosis and management of the range of epilepsy in children and young people aged up to 18 years.
- The Royal College of Paediatrics and Child Health (RCPC) **National Paediatric Diabetes Audit (NPDA) annual reports** provide evidence about long-term conditions affecting children and young people across the UK.
- **Young People with Type 2 Diabetes, 2022-23 - NHS England Digital**

Services

The **Paediatric Epilepsy Team** at Blackpool Victoria Hospital works with children and young people who have epilepsy, and their families to make sure that they can stay safe and healthy. They visit children and young people at home and also keep in touch over the phone.

The **Paediatric Diabetes Team (0-19 years)** at Blackpool Victoria Hospital looks after all children and young people who have been diagnosed with diabetes. They support, encourage and teach these children and young people and their families about how to look after themselves and their diabetes.

[1] There is further guidance on conditions that aren't covered by the disability definition (e.g. addiction to non-prescribed drugs or alcohol) and additional special rules on recurring or fluctuating conditions such as arthritis. See <https://www.gov.uk/government/publications/equality-act-guidance> for further information.

[2] NHS Outcomes Framework - 2.3.ii **Unplanned hospitalisation for asthma, diabetes and epilepsy in under 19s - NHS England Digital**

[3] Royal College of Paediatrics and Child Health **National Paediatric Diabetes Audit (NPDA) - data files**

[4] Royal College of Paediatrics and Child Health **National Paediatric Diabetes Audit (NPDA), 2023/24 report**

[5] Royal College of Paediatrics and Child Health, **Epilepsy12 national organisational audit and clinical audit, 2022**

[6] Royal College of Paediatrics and Child Health **National Paediatric Diabetes Audit (NPDA) - data files - children treated at Blackpool Victoria Hospital**

[7] Crude modelled estimate based on NHS England national prevalence data and 2023 mid-year population estimates

[8] Crude modelled estimate based on Joint Epilepsy Council (2011) and 2023 mid-year population estimates.

[10] See, for example, Shah, S.A., Quint, J.K., Nwaru, B.I., and Sheikh, A. (2021) Impact of COVID-19 national lockdown on asthma exacerbations: interrupted time-series analysis of English primary care data. *Thorax*, 76:860-866. <http://dx.doi.org/10.1136/thoraxjnl-2020-216512>

[11] Creese, H., Lai, E., Mason, K. et al (2022) Disadvantage in early life and persistent asthma in adolescents: a UK cohort study. *Thorax*, 2022(77):854-864. <http://dx.doi.org/10.1136/thoraxjnl-2021-217312>

[12] NICE (2021) [What is the prevalence of asthma?](#)

[13] Fisk W.J., Eliseeva E.A., Mendell M.J. (2010): Association of residential dampness and mold with respiratory tract infections and bronchitis: a meta analysis. *Environmental Health* 9:72

[14] For example of potential two-way relationship between Type 1 Diabetes and obesity see Marcus, C. Danielson, P. and Hagman, E. (2022) Pediatric obesity - long-term consequences and effect of weight loss. *Journal of Internal Medicine*, 292(6): 870-891. <https://doi.org/10.1111/joim.13547>, and Richardson et al (2022) Childhood body size directly increases type 1 diabetes risk based on lifecourse Mendelian randomization approach. *Nature Communications*, 13:2377 (2022). <https://doi.org/10.1038/s41467-022-29932-y>

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