

NCMD

National Child Mortality Database

Knowledge, understanding and
learning to improve young lives

Learning from deaths: Children with a learning disability and autistic children aged 4 - 17 years

**National Child Mortality Database
Programme Thematic Report**

Data from April 2019 to March 2022

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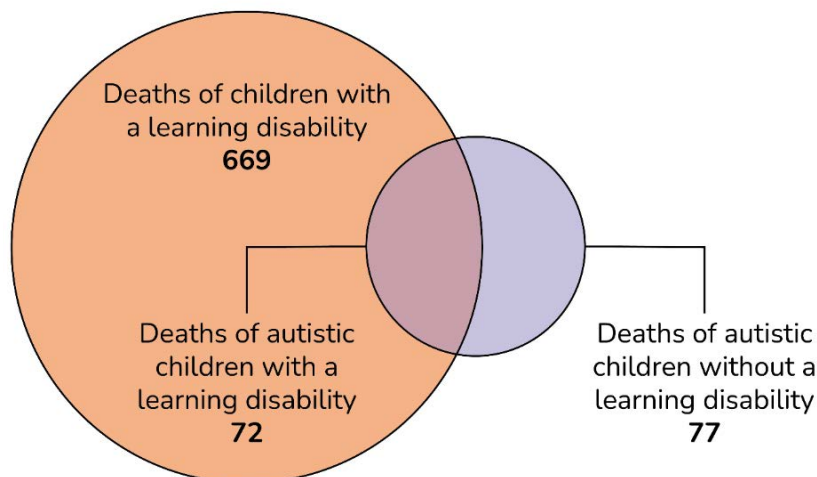
Introduction

Every child who dies is a precious individual and their deaths represent a devastating loss for parents, siblings, grandparents, carers, guardians, extended family and friends. With all child deaths there is a strong need to understand what happened, and why. We must ensure that anything that can be learned to prevent future deaths from happening is identified and acted upon.

This report analyses the deaths of children with a diagnosed learning disability and the deaths of autistic children, aged

between 4 and 17 years old. It includes data on 818 children (Figure 1) with either or both diagnoses. The children included in this report died between 1 April 2019 and 31 March 2022 and were reviewed by a Child Death Overview Panel (CDOP) before 27 November 2023. The children were split into two separate groups for further analyses. The first group is children with a learning disability, and the second is autistic children. More information about the scope, methodology and limitations used for this report is available [here](#).

Figure 1: Deaths of children with a learning disability and deaths of autistic children between 1 April 2019 and 31 March 2022 whose death was reviewed by a CDOP before 27 November 2023



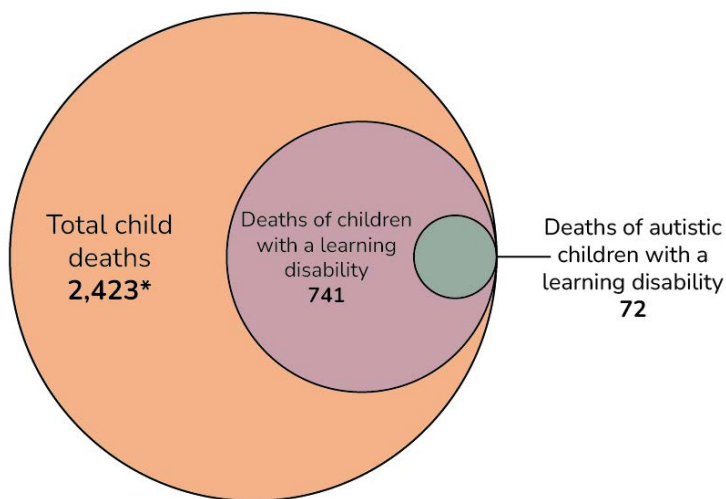
Findings for deaths of children with a learning disability

A total of 741 children with a diagnosed learning disability were included (of whom 72 also had a diagnosis of autism). This represents approximately 31% of the total number of deaths of children aged 4 –17 years and reviewed by a CDOP during the same period (Figure 2).

There are no available national data that report the prevalence and health outcomes of children with a learning disability. However, previous estimates from 2015 suggest that 2.5% of

children have a learning disability. Using Census 2021 data, this translates to approximately 234,000 4 -17-year-olds in England with a learning disability. The deaths across the three years included in this report represent approximately 0.32% of all 4 –17-year-olds with a learning disability in England. The deaths of all 4 –17-year-olds who died during this same period represent approximately 0.03% of the total population in that age group.

Figure 2: Deaths of children with a learning disability aged between 4 – 17 years old who died between 1 April 2019 and 31 March 2022 and were reviewed by a CDOP before 27 November 2023, compared with the total deaths within the same age group and time frame



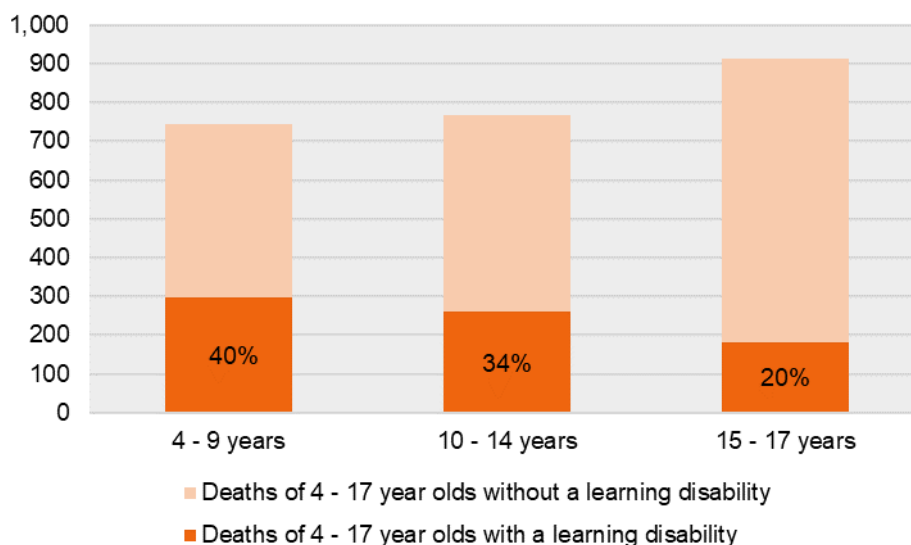
* Deaths of children aged between 4 and 17 years old, who died between 1 April 2019 and 31 March 2022, and where the death was reviewed by a CDOP before 27 November 2023

Characteristics of children with a learning disability who die

Age, Sex, Ethnicity, and Deprivation

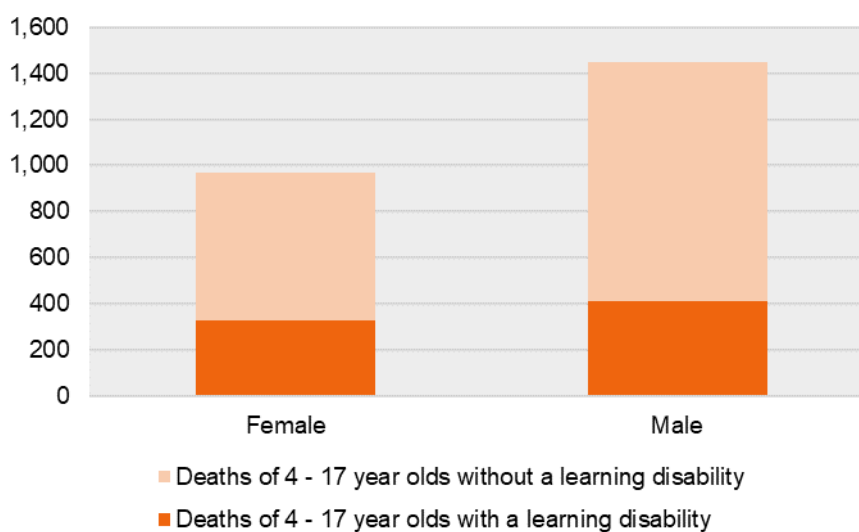
- There were 298 deaths of children aged 4–9 years, 260 deaths of 10–14-year-olds, and 183 deaths of 15–17-year-olds with a learning disability (Figure 3).
- 40% of all children between 4–9 years old who died had a learning disability. 34% of all children between 10–14 years old had a learning disability. 20% of all children between 15–17 years old had a learning disability.

Figure 3: Number of deaths of children aged 4–17 years with and without a learning disability between 1 April 2019 and 31 March 2022 (3 years), by age group



- For children with a learning disability who died, there was a higher proportion of boys who died (56%, n=413) than girls (44%, n=328) (Figure 4).

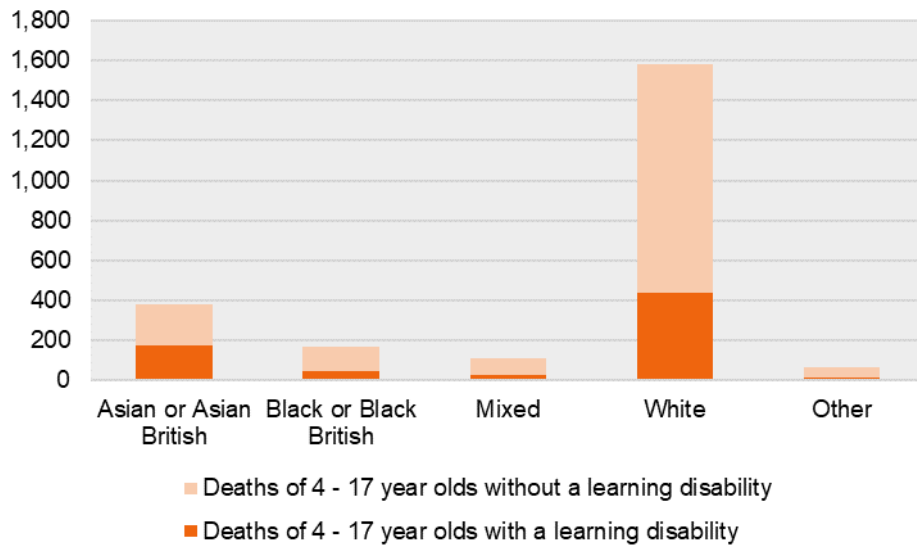
Figure 4: Number of deaths of children aged 4–17 years with and without a learning disability between 1 April 2019 and 31 March 2022 (3 years), by sex



- Of all the children with a learning disability who died, where ethnicity was recorded (n=715), 442 (62%) of them were from a white ethnic background. 176 (25%) of them were of Asian or Asian British ethnicity. 50 (7%) children were of black or black British ethnicity. 31 (4%) children were of mixed ethnicity, and 16 (2%) children were from other ethnic backgrounds (Figure 5).

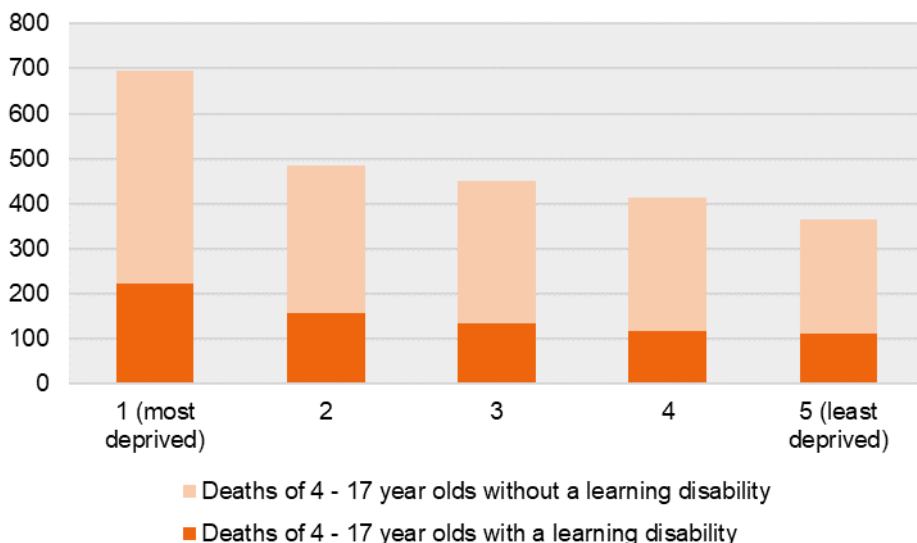
Whilst there are no national data available on the prevalence of learning disability by ethnicity of the child, the profile of deaths by ethnic group appears to be different from the overall population of children. There is a higher proportion of deaths of children of Asian or Asian British ethnicity (25%) than in the overall population (12%), and a lower proportion of deaths of children of white ethnicity (62%) than in the overall population (74%).

Figure 5: Number of deaths of children aged 4–17 years with and without a learning disability between 1 April 2019 and 31 March 2022 (3 years), by ethnicity



- Using the Index of Multiple Deprivation, 30% (n=222) of children with a learning disability who died lived within the most deprived neighbourhoods of England. This is a higher proportion than the overall population (24%) (Figure 6).
- In comparison, 15% (n=112) lived within the least deprived neighbourhoods, which is lower than the proportion of the overall population (19%).

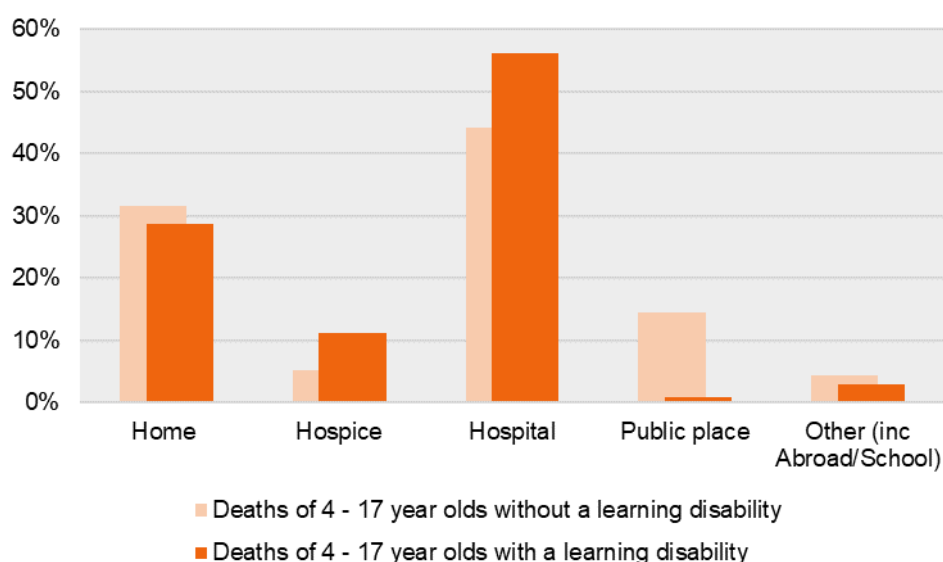
Figure 6: Number of deaths of children aged 4–17 years with and without a learning disability between 1 April 2019 and 31 March 2022 (3 years), by deprivation quintile



Place of death

- The most common place of death for children with a learning disability was in hospital (56%, n=415), followed by at home (29%, n=212) and then in a hospice (11%, n=83) (Figure 7).
- There was a higher proportion of deaths of children with a learning disability in a hospital (56%) and hospice (11%) compared to children without a learning disability (44% and 5% respectively).
- There were 21 (3%) deaths in other locations, and fewer than 5 deaths occurred within a care or residential home.

Figure 7: Proportion of deaths of children aged 4–17 years with and without a learning disability between 1 April 2019 and 31 March 2022 (3 years), by place of death



Joint Agency Response

- When a child dies suddenly and there is no immediately apparent cause, the [child death review statutory and operational guidance](#) requires a Joint Agency Response (JAR) to take place. This includes when a child with a life limiting condition dies earlier than expected. The JAR process ensures that appropriate investigations take place, and no assumptions are made about what the cause of death might be.
- Where it was recorded (n=553), 35% (n=196) of the deaths in this group were subject to a JAR.

Social care

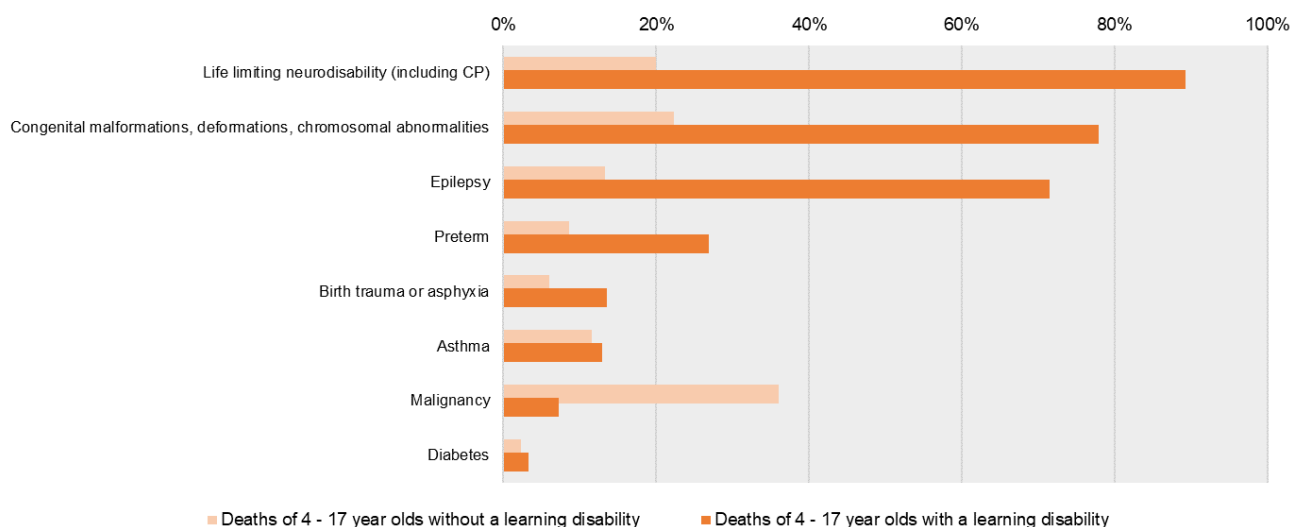
- A child with a learning disability can be known to social care for different reasons. For example, they may be receiving support because they are a disabled child or because of safeguarding concerns. Different teams within social care provide support to these families depending on their needs.
- 57% (n=420) of children were known to social care at the time of their death, including 34 who were a looked after child. A further 20% (n=148) were previously known to social care services.

Underlying health conditions

- Most children in this group had multiple comorbidities, with 92% having five or more chronic conditions.
- The most common underlying conditions were life limiting neurodisability (89%, n=621), congenital malformation or chromosomal abnormality (78%, n=542), and epilepsy (71%, n=497).
- 27% were born prematurely and 14% had previous birth trauma or asphyxia (Figure 8).
- Where data on underlying conditions was available (n=696), 89% (n=621) had a life limiting neurodisability (Figure 8), including 342 (49%) with cerebral palsy. Cerebral palsy is a physical condition that affects movement, posture and co-ordination. It is not a learning disability, however some children with cerebral palsy may also have a learning disability. 78% (n=542) had a congenital malformation or chromosomal abnormality, including 165 (24%) with congenital heart disease and 29 (4%) with Trisomy 21 (Down syndrome). Learning disability is common in people with epilepsy and 71% (n=497) of the children who died had epilepsy. [NICE guideline NG217](#) and [QS211](#) on Epilepsies in Children and Young People include recommendations to manage epilepsy in children with a learning disability, and NHS England has published a [National bundle of care for children with epilepsy](#).
- The prevalence of Epilepsy is estimated at 0.5% for children¹ and 0.9% for all ages².

1 Joint Epilepsy Council (2011)
2 Wigglesworth et al (2023)

Figure 8: Proportion of deaths of children aged 4–17 years with and without a learning disability between 1 April 2019 and 31 March 2022 (3 years), by underlying health conditions



Source: Hospital Episodes Statistics. ICD-10 codes used for classification in Appendix 2

- Children who survive serious birth events or neonatal conditions often have life-long disability³ and may die in childhood, through the association with respiratory and neurological conditions⁴.
- There were 187 (27%) children who were born prematurely (before 37 weeks gestation) and 94 (14%) had previous birth trauma or asphyxia. Asthma was diagnosed in 90 (13%) children, 50 (7%) had a malignancy (either previously or at the time of death), and 23 (3%) had diabetes.

CDOP category of death:

- CDOPs are required to assign a category to each death; information on the categorisation process can be found in the [child death analysis form](#).
- The most common primary category of death recorded by CDOP for children with a learning disability was *Chromosomal, genetic and congenital anomalies* (35%), followed by *Chronic medical condition* (26%) and *Acute medical or surgical condition* (18%) (Figure 9).
- These three categories accounted for 79% of deaths of children with a learning disability, in comparison to 23% of deaths of children without a learning disability.

- In addition, 39% of the deaths were infection related, a higher proportion than children without a learning disability (11%). *Infection* was recorded as the primary category of death for 53 (7%) children. However, this does not include infections that were a complication of an underlying health condition. *Malignancy* was recorded as the primary category of death for 37 (5%) children, compared to 32% of children without a learning disability who died.
- There were 19 (3%) deaths where the death was categorised as due to a *Perinatal or neonatal event*. This category can be chosen regardless of the age at which the child dies. It includes deaths that are related to perinatal events, for example a child who suffers from perinatal asphyxia at birth but does not die until their teenage years, or a perinatally acquired infection that causes the child to die in adolescence.
- The NCMD thematic report [The Contribution of Newborn Health to Child Mortality across England](#) reported a clear association between childhood death following neonatal illness, and learning disability.
- The report showed that children who died aged 5–9 years and had experienced a neonatal illness, were more likely to have had a learning disability than those who died without preceding neonatal illness.

³ Murray et al (2012)

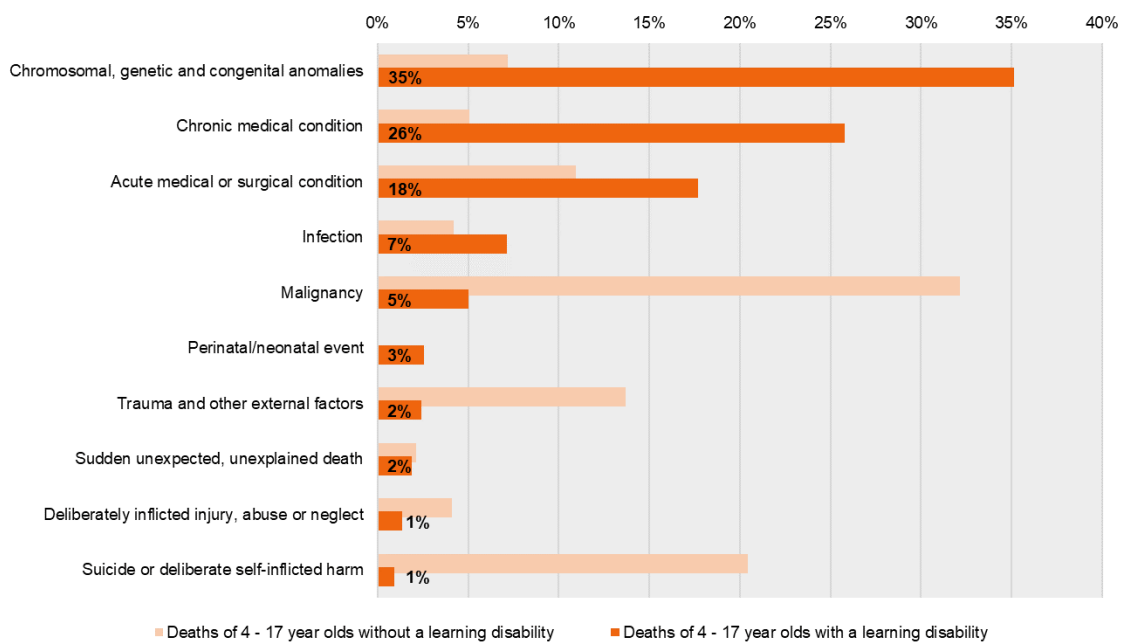
⁴ Luyt et al (2019)

- There were 18 (2%) children with the primary category of death recorded as *Trauma and other external factors* and 10 (1%) children whose deaths were due to *Deliberately inflicted injury, abuse or neglect*.
- There were 7 (1%) children whose deaths were categorised as *Suicide or deliberate self-inflicted harm*. This category of death includes deaths due to suicide and deaths because of self-inflicted injury where the intention of the child may not have been to take their own life. Of the 7 children in this group, 1 death was categorised by both CDOP and the coroner as having been due to suicide. The

remaining 6 children's deaths were categorised by CDOP as self-inflicted injury where the intent to take their own life was unclear. For each of these 6 children, the coroner agreed and returned a verdict other than suicide. It is important to note that this group includes children with rare genetic conditions that have a known association with high-risk, self-harming behaviours.

- An explanation for the death was not found for 14 (2%) children and these remained unexplained following all investigations and were categorised as *Sudden unexpected and unexplained* during the CDOP review.

Figure 9: Proportion of deaths of children aged 4–17 years with and without a learning disability between 1 April 2019 and 31 March 2022 (3 years), by CDOP primary category of death



Family experience

- Living with a learning disability can bring children and families great joy but they can also find themselves facing daily challenges, navigating complex health, social care and education systems. There is often a need to attend many appointments, sometimes in different locations, and keep track of all their child's needs.
- Within the two years before death, on average, children with a learning disability attended a total of 44 times within a hospital setting; almost twice per month.
- Whilst this analysis did not investigate length of stay (number of bed days), previous research has shown that children with a learning disability have a longer length of stay than those without a learning disability⁵.
- In this [personal story](#) a Mum describes a day in the life of her family and what it is like navigating different systems and processes for her son who has a learning disability.



5 Horridge et al (2023)

Contributory and modifiable factors in the deaths of children with a learning disability

As part of the child death review process, CDOPs must record any contributory factors identified during the review and decide which may be modifiable. Definitions of these terms can be found in the statutory [child death analysis form](#).

A lower proportion of modifiable factors (21%) were identified by CDOPs in their reviews of deaths of children with a learning disability compared with the proportion identified for children without a learning disability (33%).

The main factors identified were:

Challenges for families in attending multiple appointments

- Many families are required to attend multiple appointments for their child. The number and frequency of appointments and the impact this has on families can be significant, and sometimes appointments are missed.
- There are many reasons why families might not attend all of their appointments. They can often find it difficult to keep track of them and have reported that they did not know what to do when multiple appointments were on the same day.
- Families also reported difficulties in getting to and from different locations. One study illustrated additional challenges: having to attend to another sibling, believing the appointments were unnecessary, and thinking the appointments were too frequent⁶. During the COVID-19 pandemic families of children with a learning disability experienced additional difficulties accessing services, due to concerns about bringing the child to appointments, especially if they were shielding or in a higher risk group.
- There were also examples of delayed presentation to healthcare services due to lockdown restrictions. CDOPs recognised that remote technology and telemedicine may help to alleviate the burden of attendance for families. However, it was noted that not all types of appointments can occur online e.g., those for blood tests.
- The benefits of school-based clinics were also highlighted. For example, in some areas specialist epilepsy nurses meet for clinical reviews with families in their child's school. This not only helps reduce school absence, but also helps to involve school staff who are often responsible for monitoring and helping to manage the child's condition on a day-to-day basis.

- There are some good examples of programmes that can assist families of children with a learning disability, such as [Connecting Care for Children \(CC4C\)](#) at St Mary's Hospital in London. Through community links, they make sure that child health insights are shared between families and healthcare providers.
- CDOPs highlighted that "was not brought" policies should be more consistent and include a place to record the reasons for missed appointments. The use of the phrase "was not brought" has replaced the phrase "did not attend" as this recognises that children rely on someone else to take them to appointments. It is vital that universal services such as primary care (GP, pharmacy) and community provision (health visiting, community paediatrics, school nursing) are properly coordinated to support the care of children with complex needs.

Identification of illness and/or initiation of treatment

- CDOPs recorded issues with identification of illness or initiation of treatment in 11% of reviews, which included 39 deaths where this was recorded as a modifiable factor.
- CDOPs noted that the recognition of deterioration in a child with a learning disability is particularly challenging, as the child's response to illness may not be typical.
- Failure to recognise key signs of sepsis or that the child was critically unwell may result in a delay in starting interventions such as intravenous antibiotics or fluids or provision of high flow nasal oxygen. More analysis on this is available in the [NCMD thematic report infection related deaths of children and young people in England](#).
- There were also instances recorded where children were distressed, possibly because of the environment or the nature of the assessment or procedure. This can present challenges for healthcare professionals, and in some instances assessments or interventions were delayed or not carried out in the standard way. This added an additional layer of complexity in achieving a diagnosis.
- Difficulties with intravenous access, delays in transfer between units, and delays in undergoing procedures such as laparotomy were also recorded.
- In this [personal story](#), a consultant in paediatric emergency medicine describes her experiences.

6 Singal et al (2023)

Diagnostic overshadowing

- NHS England's [clinical guide for front line staff to support the management of patients with a learning disability and autistic people](#) highlights the need to be aware of diagnostic overshadowing.
- This occurs when the symptoms arising from physical or mental ill health are misattributed to a person's disability, leading to a delayed diagnosis or treatment. People with a learning disability and autistic people have the same illnesses as everyone else, but the way they respond to or communicate their symptoms may be different.
- An example of diagnostic overshadowing would be when a health professional interprets a person with a learning disability rubbing their head as a behaviour linked to their learning disability, and fails to investigate any possible underlying health cause.
- Diagnostic overshadowing can lead to compromised patient care and may contribute to increased mortality experienced by individuals with mental illness⁷.

Reasonable adjustments

- Under the [Equality Act \(2010\)](#), it is a legal requirement for public sector organisations, including the NHS, to anticipate and make reasonable adjustments to their approach or provision to ensure that services are accessible to disabled people.
- Consideration around reasonable adjustments must be person-centred and discussed in partnership with the individual child and their family or carer. Reasonable adjustments aim to remove barriers, do things in a different way, or to provide something additional **to enable a person to access the services that they need easily and appropriately**.
- Examples include ensuring all information and communication is accessible, allocating a clinician by gender, booking appointments at the start or end of the day when the clinic is quieter, providing a quiet space to see the child away from excess noise and activity, or giving a double appointment so the child has more time with the doctor.
- From Spring 2024 the new reasonable adjustments 'digital flag' in the patient record will make sure staff know whether a child is disabled, what impairments or conditions they may have, and what reasonable adjustments they personally require to enable them to have appropriate and equitable access to NHS services and care.

- Many autistic people and those with a learning disability, may also have a healthcare or hospital passport. This is a document that contains information about the individual patient and their health needs. It includes information on how the person communicates and any reasonable adjustments they may need. NHS England implementation guidance on health and care passports can be found [here](#).
- The [NHS Long-term Plan](#) commits the whole NHS to improve its understanding of the needs of people with a learning disability and autistic people, and work together for the betterment of their health and wellbeing.
- The [Health and Care Act 2022](#) introduced a requirement that all regulated service providers provide training for their staff on learning disability and autism, which is appropriate to the person's role. This training will support Integrated Care Boards to make sure that all local healthcare providers are making reasonable adjustments to support people with a learning disability and autistic people.
- National learning disability improvement standards have been developed and are implemented in 94% of NHS trusts. These promote greater consistency in care and address themes such as rights, the workforce, specialist care and working more effectively with people and their families.
- All local authorities must provide resources to support healthcare professionals to make the adjustments needed for children with a learning disability.

Close relative marriage

- CDOPs recorded the presence of close relative marriage as a contributory factor in 9% (n=67/741) of deaths reviewed.
- Close relative marriage (also known as consanguinity), often marriage between cousins, is common around the world⁸. It is also preferred among some families and communities in the UK.
- For consanguineous families with no family history of genetic conditions there is a slightly increased risk of having a child with a genetic disorder, and some children with genetic disorders will also have a learning disability. However, once a family has a child with a genetic disorder, they are at increased risk for future pregnancies, as is their extended family. It is important to note that 90% of children born to consanguineous families will not be affected by a genetic condition^{9,10}.

7 Hallyburton (2022)

8 Khan and Salway (2020)

9 Sheridan et al (2013)

10 Teeuw et al (2010)

Learning identified by CDOP reviews of deaths of children with a learning disability

Importance of children being on the GP Learning Disability Register and receiving annual learning disability health checks

CDOPs identified instances of children with a learning disability not being on the learning disability register at their GP surgery and not receiving their [annual learning disability health checks](#). A child can go onto the [GP Learning Disability Register](#) at any age and is eligible for the annual learning disability health check from 14 years old. GP Learning Disability Registers can help facilitate consideration and provision of reasonable adjustments and support, for a person with a learning disability.

The annual learning disability health check is an opportunity to spot any developing health problems more quickly, ensure timely referral to appropriate services if needed, and ensure that people are on the right medication for their care. A health action plan should be developed to help the child manage their health, with the support of their family and multi-disciplinary professionals if this is needed. It is important to ensure children with a learning disability are included on the register, even if they are mainly cared for by a paediatrician. This is because it allows the GP practice to know the child has a learning disability at the earliest opportunity and to build a relationship with them before they transition to adult services.

The importance of early and comprehensive advanced care planning

CDOPs highlighted the importance of early discussions for children with life limiting conditions around advanced care planning and referral to palliative care teams. CDOPs highlighted the following areas:

- The importance of sharing accessible up-to-date Advance Care Plans (ACPs) with all services including the ambulance service.
- The regular review of ACPs by clinicians, especially when a child's condition significantly changes or deteriorates. This will also allow family wishes to be revisited.
- Ensuring families are aware that if their child dies suddenly and with no immediately apparent explanation there may be a legal requirement for a Joint Agency Response (engaging police, healthcare, and social services), referral to the coroner, and possible post-mortem examination.
- The importance of understanding cultural views on ACPs and how they may be perceived in some communities.

The importance of having a lead healthcare professional for each child

The lack of a lead healthcare professional for the child was highlighted in 7 CDOP reviews. This resulted in families feeling that they had to take on this role. CDOPs emphasized the importance of identifying a lead professional to support and guide families of children with complex needs. The absence of a lead health professional may lead to poor co-ordination of care, lack of advocacy for the family, and potential missed opportunities to achieve a long-term view of a child's health status, especially their trajectory towards the end of life. This role can also act as an interface with other professional networks. The [Francis Report](#) recommended that every hospital patient should have the name of the consultant and nurse responsible for their care above their bed. In addition, the [Paediatric Critical Care Society 2021 Standards](#) state that all children with complex healthcare needs should have a single, clearly identified lead consultant who should be kept fully informed about all admissions.

The importance of early and robust transition planning for children moving between paediatric and adult services

CDOPs highlighted the transition from a paediatric to an adult service as a challenging time for children with a learning disability. For example, in adult services there is no equivalent of specialist neurodisability or community paediatricians who manage children with complex disability and provide holistic care. The requirement for robust transition planning for patients with complex needs, as well as recognition that some young people aged 16 to 18 years will require adult medical treatment but in a paediatric environment, was identified as important.

CDOPs highlighted that the appropriate timing of transition should also be considered; for example, whether it is deemed appropriate to transition a child during the end stage of their disease. CDOPs also highlighted the lack of clarity around engagement of adult services (primary care/secondary care/specialist community outreach) for patients aged 16 to 18 years, both during and following transition, resulting in barriers to seamless care and risk of children falling between services. In one case, the child's mother had commented to a professional during a discussion that "nobody wants my child".

The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) published a report on [transition from child into adult healthcare](#) in June 2023. This report concluded that there is no clear pathway for the transition of children to adult healthcare services. The report also found that the process of transition and the subsequent transfer is often fragmented, both within and across specialties. The report makes several recommendations to address this issue.

Challenges for families in education

CDOPs highlighted several challenges for families of children with a learning disability and complex needs in relation to education. These included:

- Difficulties accessing appropriate school placements.
- Difficulties receiving funding for school transport.
- The lack of a bereavement policy within schools for staff and pupils.
- Delays in Education Healthcare Plans (EHCPs) being put in place, resulting in the child not being in education and impacting on their quality of life.
- Challenges in training of non-medical staff in the use of gastrostomies and tracheostomies which may delay the child starting school.

Challenges for families accessing social care, housing and financial aid

In addition to the burden of healthcare appointments for families, CDOPs also identified specific challenges relating to social care, housing and financial aid. These included:

- Difficulties for some families to meet the threshold for social care support despite having complex needs. One family shares their personal experience on this issue [here](#). Access to good social care support facilitates families to be able to go out safely, and this improves their ability to access and engage with healthcare professionals.
- Poor monitoring by social care of families open to them, and postponement of case reviews.
- Poor communication between social care, multi-professional team members, and families.
- Delay in commencement of social care packages, and the long timeframe for grants to be approved.
- The importance of regular review of existing care packages to determine whether provision is still optimal, identify any gaps, and explore options for improvements.
- The importance of suitable housing for children with additional needs. CDOPs reported instances of families experiencing poor housing provision including difficulties in accessing the garden, limited access for moving hoists between rooms, lack of disabled parking access, living in houses with damp and mould, and poor toilet or bathing facilities. These had a detrimental effect on the well-being of children and created additional stress for families.
- The lack of appropriate privately rented housing for families with severely disabled children.

- The delay in processing equipment applications and home adaptations. CDOPs particularly saw instances of poor timeliness of wheelchair adaptations to housing and delays in specialist equipment provision.
- The need to invite Housing teams to multi-agency meetings, so that housing needs can be reviewed in relation to the impact of decisions on health needs and life expectancy.
- The recognition that family benefits are stopped immediately after the death of the child which may push some families into financial poverty. CDOPs noted specific examples where mobility cars were collected in the first week post death leaving the family without transport, and cessation of carers allowance and rejection of applications for other financial aid.

Learning from a mother's experience after the death of their child

This mother fed back during the child death review that she would like professionals to be aware of the following things when dealing with families after their child has died:

- The importance of considering the timing of communication to families by services picking up medical equipment after death. Make sure it is not too soon after the death or on a day of significance for the family.
- Make sure staff retrieving medical equipment are aware of the circumstances and reason the equipment is no longer needed.
- Consider keeping information related to support organisations separate from a memory box. For some families it can be very difficult to open a memory box and if support information is inside the box, it may not be seen at an early stage.
- Recognise the importance of the key worker role in the child death review process. This role can assist families with chasing information and understanding and addressing their concerns. More information on the key worker role can be found in the [Child Death Review Statutory & Operational Guidance \(2018\)](#).
- The importance of open and early conversations about organ and tissue donation, including for medical research.

Findings for deaths of autistic children

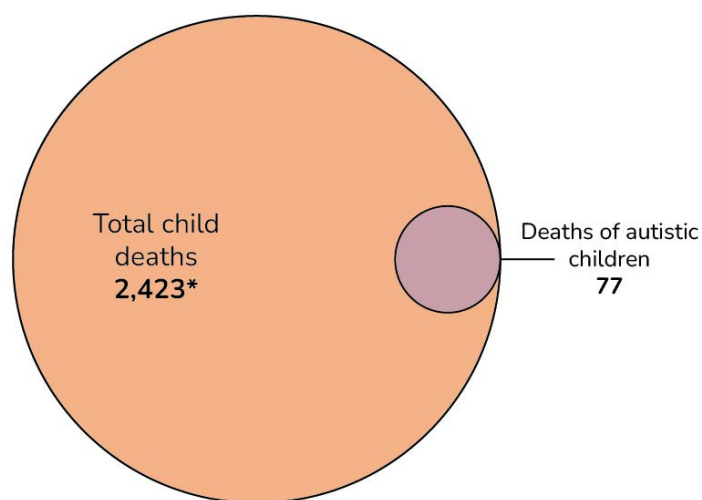
Identity-first language (e.g., autistic individual) is used throughout this report, as this terminology is preferred by the majority of the autistic community in the UK¹¹.

This section of the report analyses the deaths of autistic children with a confirmed diagnosis, aged between 4 and 17 years old. The children included in this report died between 1 April 2019 and 31 March 2022 and were reviewed by a CDOP by 27 November 2023. This group comprised 77 deaths in total. The latest reported prevalence of autism in children in England is 1.16%¹². Using Census 2021 data, this translates to

a crude estimate of 150,000 autistic children aged 4–17 years in England. Children suspected to be autistic or who were on a waiting list for diagnosis were not included in the main analyses, however, these deaths are reported separately (see [Supporting Material](#)).

Deaths across the three years included in this report represent approximately 0.05% of all autistic children in England. These 77 deaths represent approximately 3% of the total number of deaths of all children aged 4–17 years reviewed by CDOP during the same period (Figure 10).

Figure 10: Deaths of autistic children aged between 4–17 years old who died between 1 April 2019 and 31 March 2022 and were reviewed by a CDOP before 27 November 2023, compared with the total deaths within the same age group and time frame



* Deaths of children aged between 4 and 17 years old, who died between 1 April 2019 and 31 March 2022, and where the death was reviewed by a CDOP before 27 November 2023

¹¹ Kenny et al (2016)
¹² Baird et al (2006)

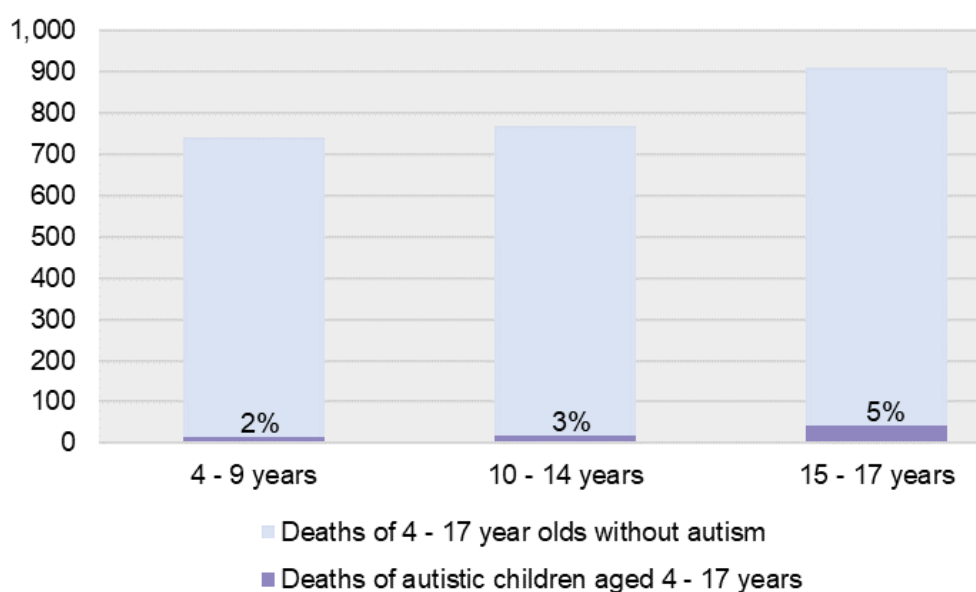


Characteristics of autistic children who die

Age, Sex, Ethnicity, and Deprivation

- There were 43 autistic children who died between the ages of 15 and 17 years, 20 who died between the ages of 10–14 years, and 14 who died between the ages of 4–9 years (Figure 11).
- This represents 5% of all children who died aged 15–17 years old, 3% of all those who died aged 10–14, and 2% of all those who died aged 4–9.

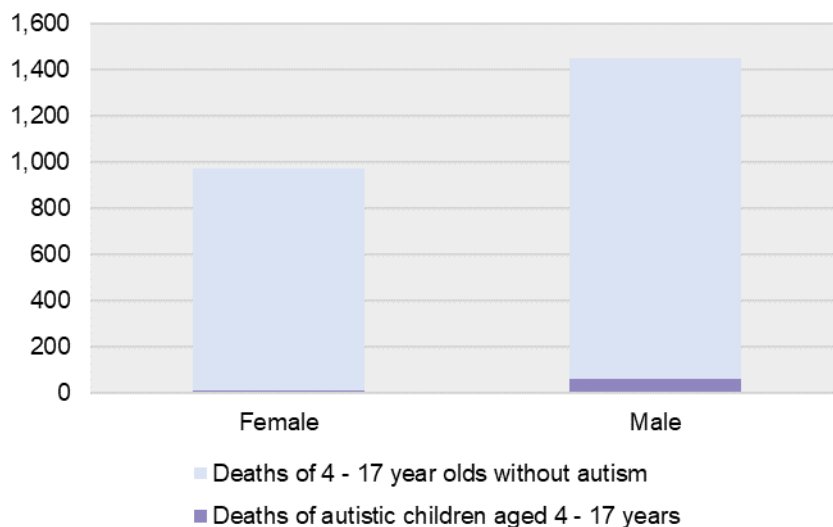
Figure 11: Number of deaths of autistic and non-autistic children aged 4–17 years between 1 April 2019 and 31 March 2022 (3 years), by age group



- Whilst the split between males and females in the general population is roughly equal, there are approximately four times as many autistic boys identified in the population than girls¹³. Similarly, for autistic children who died, there were over four times as many boys (n=62, 81%) as girls (n=15, 19%) (Figure 12).

13 Roman-Urrestarazu et al (2021)

Figure 12: Number of deaths of autistic and non-autistic children aged 4–17 years between 1 April 2019 and 31 March 2022 (3 years), by sex

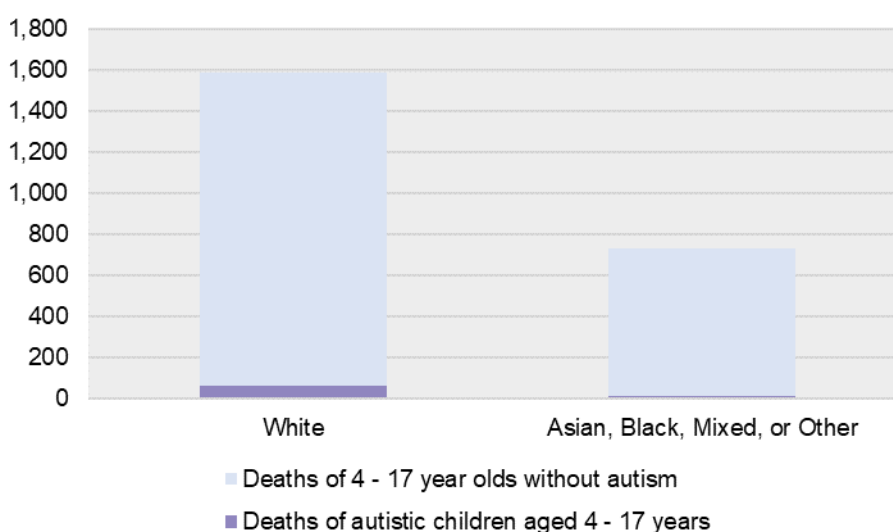


- Both of these features are likely to be impacted by diagnostic challenges. Many children are not diagnosed until their teenage years. In addition, although the reported prevalence is higher in boys, some research suggests that late diagnosis in girls may be due to girls expressing their autism through subtle variations in behaviour compared to boys, which are not captured in current diagnostic tools or criteria¹⁴.
- Whilst there are no national data available on the prevalence of autism by ethnicity of the child, the profile of deaths by ethnic group appears to be different from the

overall population of children. Where it was known (n=75), there were 63 (84%) deaths of autistic children from a white ethnic background, and 12 (16%) from Asian, black, mixed, or other ethnicities (Figure 13).

- There is a higher proportion of deaths of autistic children of white ethnicity (84%) than in the overall population of all children (74%), and a lower proportion of deaths of autistic children from Asian, black, mixed, or other ethnicities (16%) than in the overall population (26%). Autism identification appears to be lower in minority ethnic groups relative to the majority population¹⁵.

Figure 13: Number of deaths of autistic and non-autistic children aged 4–17 years between 1 April 2019 and 31 March 2022 (3 years), by ethnicity

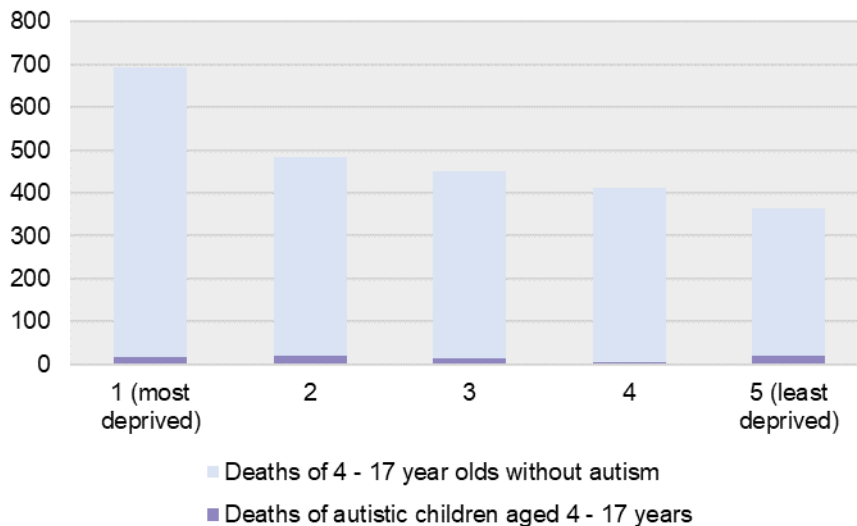


- Using the Index of Multiple Deprivation, there did not appear to be any association between number of deaths and levels of

¹⁴ Hull et al (2020)
¹⁵ Tromans et al (2021)

deprivation for autistic children who died. 23% (n=18) of autistic children who died lived in the most deprived neighbourhoods; a similar proportion to autistic children who died while living in the least deprived neighbourhoods (26%, n=20) (Figure 14).

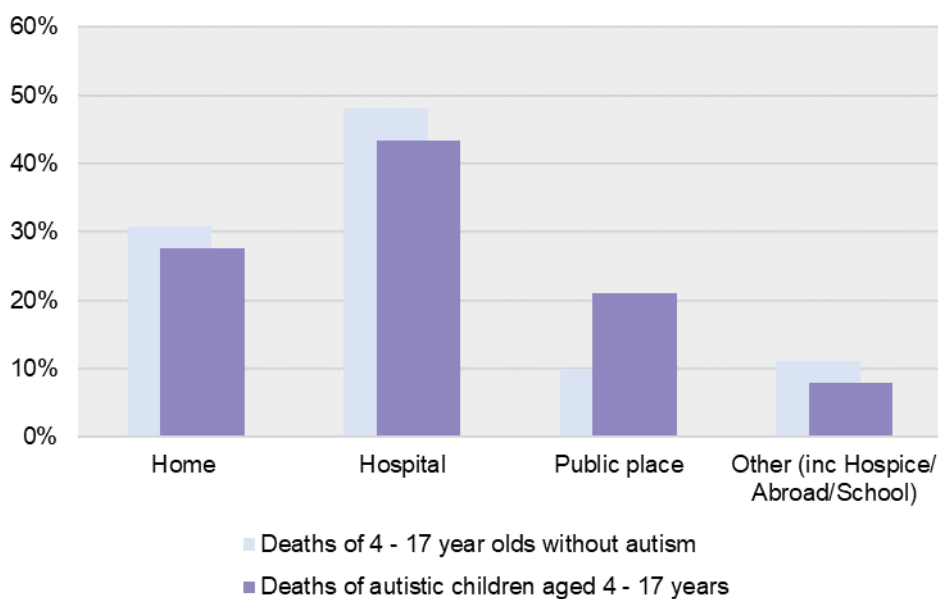
Figure 14: Number of deaths of autistic and non-autistic children aged 4–17 years between 1 April 2019 and 31 March 2022 (3 years), by deprivation quintile



Place of death

- The most common place of death recorded for autistic children was a hospital (43%, n=33), followed by deaths at home (28%, n=21), deaths in a public place (21%, n=16) and deaths in other places (8%, n=6) including in a hospice (Figure 15). There were no deaths of autistic children that occurred within a mental health inpatient unit.

Figure 15: Proportion of deaths of autistic children and children without autism aged 4–17 years between 1 April 2019 and 31 March 2022 (3 years), by place of death



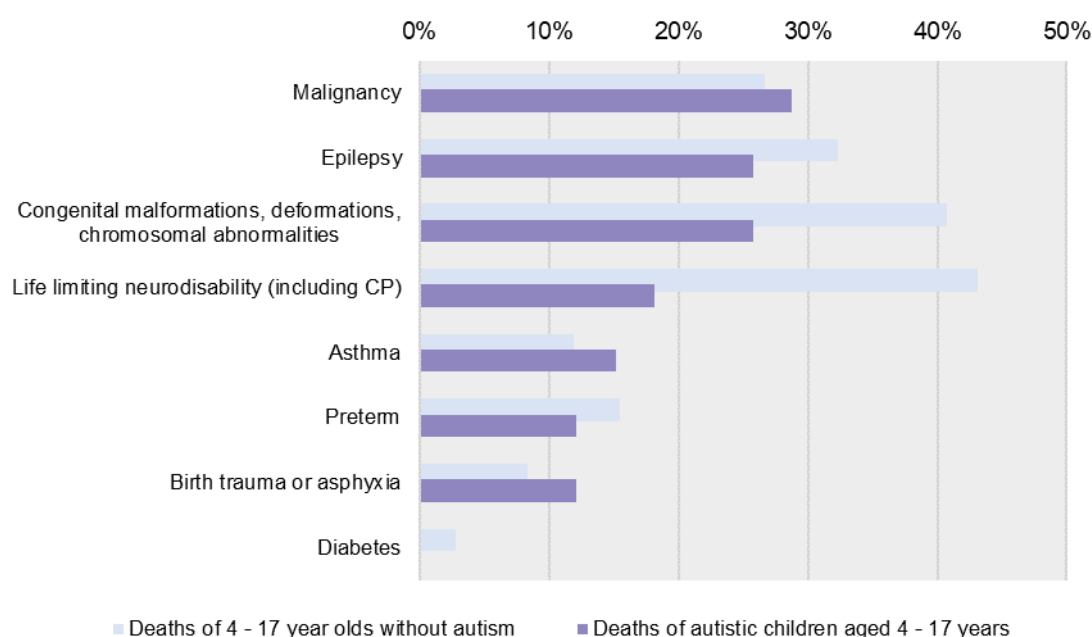
Joint Agency Response

- When a child dies suddenly and there is no immediately apparent cause, the [child death review statutory and operational guidance](#) requires a Joint Agency Response (JAR) to be conducted. This includes children with life limiting conditions who die earlier than expected. The JAR process ensures that appropriate investigations are undertaken, and no assumptions are made about what the cause of death might be.
- Where it was recorded (n=59), 58% (n=34) of the deaths were subject to a Joint Agency Response.

Underlying health conditions

- The most common underlying conditions were malignancy (either previously or at the time of death) (29%, n=19/66), epilepsy (26%, n=17/66) and congenital malformation or chromosomal abnormality (26%, n=17/66) (Figure 16).
- In addition, 12% (n=8/66) were born prematurely and 12% (n=8/66) had previously experienced birth trauma or asphyxia. However, due to small numbers interpretation should be cautious.

Figure 16: Proportion of deaths of autistic children and children without autism aged 4–17 years between 1 April 2019 and 31 March 2022 (3 years), by underlying health conditions



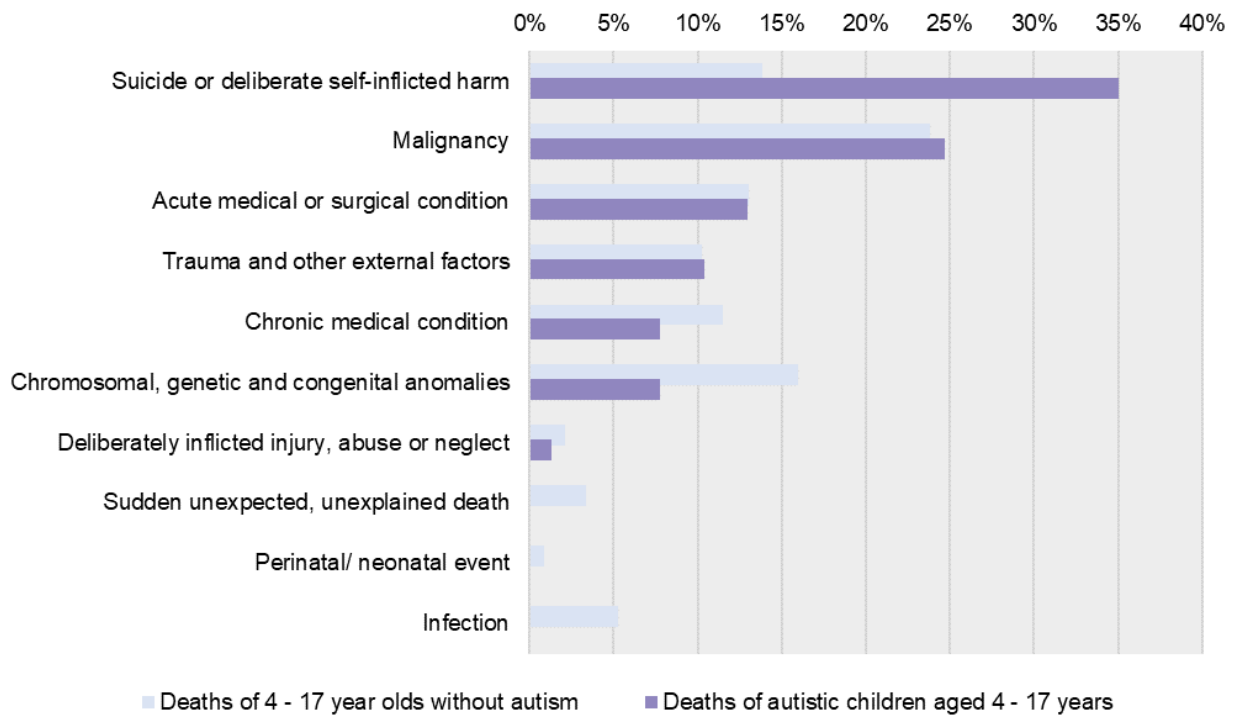
Source: Hospital Episodes Statistics. ICD-10 codes used for classification in Appendix 2.

CDOP category of death

- CDOPs are required to assign a category to each death; information on the categorisation process can be found in the [child death analysis form](#).
- 35% (n=27) of the 77 autistic children who died were categorised by CDOP as dying due to *Suicide or deliberate self-inflicted harm*; this was the most common primary category of death for this group (Figure 17). This proportion was higher than the proportion of deaths categorised as *Suicide or deliberate self-inflicted harm* for non-autistic children (14%).
- This category of death includes deaths due to suicide and deaths as a result of self-inflicted injury where the intention of the child may not have been to take their own life. Of the 27 autistic children in this group, the deaths of 22 were categorised by both CDOP and the coroner as having been due to suicide. The remaining 5 autistic children were categorised by CDOP as self-inflicted injury. For each of these 5 children, the coroner returned a verdict other than suicide.
- The previous [NCMD thematic report on suicide in children and young people](#) identified the importance of recognising the challenges for autistic children.

- The next most common primary categories of death were Malignancy (25%, n=19) and *Acute medical or surgical conditions* (13%, n=10). These proportions were similar to those of non-autistic children who died (24% and 13% respectively).
- Out of the 19 deaths of autistic children due to malignancy, the most common primary diagnosis was leukaemias, myeloproliferative or myelodysplastic diseases (n=10, 53%). This proportion appeared to be higher than for non-autistic children who died due to this primary diagnosis (23%, n=82/361), where this information was available. Whilst numbers are small, and interpretation is difficult, further research is required to investigate the relationship between autism and malignancy.
- Fewer than 10 deaths were recorded under each of the other categories.

Figure 17: Proportion of deaths of autistic children and children without autism aged 4–17 years between 1 April 2019 and 31 March 2022 (3 years), by CDOP primary category of death



Contributory and modifiable factors in the deaths of autistic children

As part of the child death review process, CDOPs must record any contributory factors identified during the review and decide which may be modifiable. Definitions of these terms can be found in the [child death analysis form](#).

A higher proportion of modifiable factors (38%) was identified by CDOPs in their reviews of autistic children compared with the proportion identified for non-autistic children (29%).

The main factors identified were:

Distressed behaviour in autistic children

- Some autistic children express their emotional distress through behaviour or actions which are risky or harmful to themselves or others. Distressed behaviour can take many forms including physical aggression, anger, self-harm or injury. Distressed behaviour may occur for several reasons, such as difficulty in processing information, changes in routine or transition between activities, or experiencing trauma due to, for example, the loss of key relationships (e.g., bereavement) or bullying. Not being able to communicate these difficulties can lead to anxiety, anger and frustration and then to an outburst of distressed behaviour. Distressed behaviour can have serious negative impacts on children including risks to themselves, breakdown of relationships, and emotional and physical impacts.
- CDOPs recorded a range of distressed behaviour including self-harm, previous suicide attempts, substance or alcohol misuse, sleep difficulties, and problems with medication adherence.

Social isolation

- Social isolation can be defined as a reduction in social contacts. Loneliness and social isolation have negative consequences on physical and mental health for children.
- Autistic children may be excluded and experience more loneliness than their neurotypical peers¹⁶.
- The [National Autistic Society](#) highlight on their website that many autistic people enjoy spending time alone and consider it important for their wellbeing. However, some autistic people can feel misunderstood, or not able to be themselves around their friends.
- There are many reasons why an autistic child might feel lonely, including loss of key relationships, having mental health difficulties, lack of reasonable adjustments for supportive environments, delays in accessing care and support, inadequate support at school, or struggling with sexuality or gender identity.



Problems with service provision

- CDOPs collect information from all services (education, health and social care, law enforcement and other agencies) who had contact with the child during their life or immediately after their death. They identified factors in service provision which may have contributed to the vulnerability, ill-health or death, for 34 children. In 19 of those, the CDOP recorded at least one modifiable factor.
- Autistic children are likely to need support from health, social care and education during their lives. Lack of, delayed, or poor-quality referrals or assessments were highlighted as contributory factors in CDOP reviews. Challenges in accessing services resulting in delays in diagnosis or identification of illness and initiation of treatment, were also highlighted by CDOP reviews.

¹⁶ Kwan et al (2020)

Learning identified by CDOP reviews of autistic children who died

Waiting lists for referral and assessment of children with suspected autism

- Although all the autistic children included in this report had a confirmed diagnosis at the time of their deaths, several CDOPs highlighted the current challenges experienced by the system for referral and assessment of children who are suspected to be autistic. The number of referrals into children and young people's mental health services (CYPMHS) has significantly increased and there is currently a wait of up to 2 years for assessment. In December 2023, there were 102,020 patients aged between 0-17 years with an open referral for suspected autism, with 86,105 (84%) having a referral that had been open at least 13 weeks¹⁷.
- Some children in this group had experienced a delay in their diagnosis and CDOPs noted increased anxiety or an escalation in risk-taking behaviour for some while they were waiting to be diagnosed.
- In one instance, a [Regulation 28 Prevention of Future Deaths Report](#) was issued by a coroner highlighting that insufficient consideration had been given to the impact of the delay in an autism diagnosis on the risk of suicide.
- The deaths in this report include those that occurred during the COVID-19 pandemic. During this period changes in the way services were delivered represented challenges for autistic children. Changes in routines, reduced face to face contact and socialising opportunities meant increased time spent alone. For some autistic children, this resulted in increased anxiety and made carrying out full assessments online very challenging for professionals.
- The government's [National Strategy for Autistic Children and Young People](#) highlights that there are several factors contributing to the delays in diagnosis, including increased demand on services arising from growing public awareness of autism, which has resulted in increased referrals and more people on waiting lists. This has been further impacted by the COVID-19 pandemic, which resulted in some local systems pausing or delaying assessments, and blockages within diagnostic pathways, due to the diagnostic models used and pressures on the workforce.
- In September 2023, the Department for Health & Social Care published its "[Suicide Prevention in England: 5 year cross-sector strategy](#)" in which actions to support autistic people are prioritised. The strategy also addresses common risk factors (social isolation, loneliness, and alcohol and drug misuse) and the need to provide early intervention and tailored support. It sets out over 100 actions by government departments, the NHS, the voluntary sector and other national partners to make progress in the areas identified, particularly over the next 2 years.

Poor co-ordination and communication between organisations involved in providing educational, healthcare and children's services

- Poor communication and co-ordination of care for autistic children included failures to involve families in care planning, poor monitoring of prescribed medication, agencies focusing on multiple factors individually rather than having a whole person approach, lack of allocation of a care co-ordinator, and silo working.
- In one instance a [Regulation 28 Prevention of Future Deaths report](#) was issued by a coroner highlighting the lack of a case manager or key worker as an issue that needed addressing. This was the case despite [NICE Guideline CG170 on Autistic Spectrum Disorder in Under 19s: support and management](#) stating that local autism teams should ensure that every autistic child has a case manager or key worker to manage and coordinate treatment, care, support and transition to adult care.
- Information sharing between agencies was also highlighted as a key area for improvement, in particular the content of medical reports attached to Education Health and Care Plans (EHCPs) and details of CYPMHS referrals. The SEND / Children's teams in the NHSE Learning Disability and Autism Programme are working with Department for Education to strengthen health contribution to EHCPs.
- NHS England has introduced autism and learning disability key workers to support children and young people and their families. These will be available in every integrated care system. More information is available on this service [here](#).
- Poor information sharing with GPs was highlighted in several cases, which resulted in missed opportunities to seek their input to multi-agency discussions. Agencies' abilities to support autistic children with self-harming behaviours are strengthened by multi-agency information sharing and professional curiosity, which ensures that when applying thresholds for support or intervention, all present risks and vulnerabilities are known.
- CDOPs also highlighted challenges that can arise when support is split across NHS and private providers because this can make it difficult to have an overview of the care being provided. There is no current mandate for data-sharing between private and NHS providers; families may access private provision if they feel their child's needs are not able to be met within NHS provision.

¹⁷ NHS England (2023)



Transition between child and adult healthcare services

- Most autistic children will not be under specialist healthcare services; however, some can experience challenges when moving from paediatric to adult healthcare services, for example, when moving from CYPMHS to adult mental health services.
- CDOPs highlighted the need for clear pathways of referral, transition and support when they are 16-17 years of age. There are different age limits for different services which can be confusing and difficult to navigate, resulting in re-referrals being needed to the correct service when a mistake is made. This causes additional delays and in some cases disengagement by the child and their family.
- Transition should be carefully planned and managed to minimise any distress or other impacts on children.
- CDOPs considered local implementation of transition plans and safety nets, so children who are coming to the end of children's services know how they can access adult support. They also considered the utility of a timeline setting out when a named worker and lead practitioner should be assigned to a child ahead of their 18th birthday; although where possible joint working should commence well in advance of that date.

Importance of suicide prevention education inclusion in relationship and sex education and health education

- CDOPs highlighted the importance of discussing suicide prevention in an age-appropriate way in schools. This should include education of children on how to support themselves and their friends and knowing what to do and where to go if they are worried.

Challenges in diagnosis and treatment of autistic children

- For autistic children who died of disease or illness, the main area of learning highlighted by CDOPs was challenges in diagnosis and treatment. This included children who died as the result of an acute or chronic medical condition, cancer or a genetic or congenital condition including cardiac conditions. There was also learning for children presenting with acute abdominal pain, highlighting the importance for all clinicians to include volvulus and malrotation as a differential within their diagnosis.

Recommendations

1. Ensure reasonable adjustments are discussed with and provided for all children with a learning disability, autistic children, and where necessary their families and carers, and that the details of these needs are appropriately captured in the “reasonable adjustments digital flag” in their clinical record. **Action: all healthcare professionals**
2. In line with recommendations made in the NCMD thematic review Infection related deaths of children and young people in England, ensure that there is a recognition that infants and children with a learning disability and autistic children with underlying health conditions may be at higher risk of death from infection and as a consequence, improved guidance and training is needed to highlight this risk to healthcare professionals. A low threshold for urgent transfer to hospital, senior review, and early initiation of treatment should be considered. **Action: NHS England, Royal College of Paediatrics and Child Health and Royal College of General Practitioners**
3. Ensure a designated Named Lead Healthcare professional is identified to support autistic children and children with a learning disability, with multiple co-morbidities and complex health care needs, to help in the co-ordination of healthcare provision. **Action: NHS England**
4. Ensure improved consideration and account of the needs of children with a learning disability and autistic children, is included in future revisions of national clinical standards and guidance with respect to transition from paediatric to adult healthcare services. **Action: NHS England**
5. Ensure “Was not brought” policies recognise and meet the needs of the complex lives of children with a learning disability, autistic children and their families, and that they support effective attendance at appointments with suitable safeguarding and escalation in place where needed. **Action: Integrated Care Boards**
6. Ensure increased focus to ensure that children and young people are not waiting inappropriately long times for autism assessment, in line with NICE and NHS national framework and operational guidance for autism assessment services. **Action: Department of Health & Social Care**
7. Ensure that autistic children, and those waiting for an autism assessment, have timely access to appropriate support with mental health services, including talking therapies. Services provided should recognise the importance of post diagnostic support to these groups. **Action: Commissioners of mental health services**
8. Review relationships, sex and health education (RSHE) guidance to include on the curriculum appropriate education on self-harm and suicide prevention for all children, including how to access support if they are in need. This should be age appropriate and accessible by all children and especially children who are or who may be autistic or neurodivergent, noting that children may not be diagnosed by the time of the education offer being presented to them. **Action: Department for Education**
9. Consider ensuring that parents who have been full-time carers of a child who has died automatically receive the additional payments that are available to those with Limited Capability for Work and Work Related Activities (LCWRA) for the first 12 months following the child’s death, if they are in receipt of Universal Credit. **Action: Department of Work and Pensions**

Next steps and future priorities

NCMD works continuously to improve data completeness and quality by further developing the child death review (CDR) data collection forms. This aims to better support and guide the CDR process and provide more granular and comprehensive data to support deeper understanding of deaths of children with a learning disability and autistic children. Consequently, NCMD will work to:

1. Introduce a new question on the child death reporting form to ask about neurodevelopmental conditions in the child. There is currently no appropriate place to add this information, and this means these conditions are being recorded under other data collection fields e.g., the learning disability question. Addition of this new field will improve data quality and support improved analysis.
2. Develop a set of supplementary reporting forms to be completed for all disabled children, or those with multiple co-morbidities, who die. This will be developed by a small working group and specific consideration around relevant questions will be developed accordingly. This will support CDOPs in the review process and improve the consistency of how learning disability, learning difficulty and neurodevelopmental conditions are recorded and reviewed.

CDOPs highlighted consistent challenges in receiving information for child death reviews from GPs and social care. [Working Together to Safeguard Children \(2023\)](#) highlights the statutory requirement to provide information to CDOP when requested. It also clarifies that the person or organisation asked to provide information must comply with the request, and if they do not, the child death review partners may take legal action to seek enforcement. This requirement should be highlighted by CDOPs and NCMD to ensure all agencies understand the importance of contributing to the CDR process and why they must contribute when asked.

Future priorities

This report highlights some key areas where further research is needed including:

- Understanding the barriers to accessing services for children with a learning disability and autistic children, particularly those living in deprived areas or from different ethnic backgrounds, so inequalities in mortality can be reduced. This may also include specific work on removing barriers to families attending appointments.
- Further work is also needed to investigate the relationship between autism and malignancy.



NCMD

National Child Mortality Database

Knowledge, understanding and
learning to improve young lives

National Child Mortality Database (NCMD)

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