Derby and Derbyshire Child Death Overview Panel Annual Report April 2023 to March 2024

Authors

Juanita Murray – Chair of Derby & Derbyshire CDOP

Nic Medd – Designated Doctor for Child Death Derby & Derbyshire

Kayleigh McMahon – Lead Nurse for Child Death Review

Contents Page

Introduction

The Child Death Review Team and Child Death Overview Panel (CDOP) members have continued to review child deaths within the framework of the statutory guidance. Through the activity of the team and CDOP, learning has been disseminated across the partnership with an aim to drive improvements in service provision and prevent future child deaths.

This reporting year has allowed us to hear the unique stories of 68 children, young people, and their families. Their stories matter and the privilege of hearing from them allows us to look for ways to prevent and reduce the future deaths of children across Derby and Derbyshire. We are grateful to all those families who decided to contact us to share their feedback and concerns and share their child's voice. We will continue to hold the voices of children and their families at the very heart of what we do.

This year's annual report has a focus on our understanding of deprivation and the impact this has on children and families. There is a known correlation between those children living in more deprived areas who suffer more health inequalities and have a higher risk of ill health. It is known that the rates of death in children are higher in areas that are more deprived. One aim of the Child Death Review Team is to support CDOP and wider partners to have a consistent approach to the identification and understanding of the impact of deprivation and health inequalities on our children and families with the aim of learning from those deaths where deprivation is a factor and to support and improve the health and wellbeing of children within Derby and Derbyshire.

An audit was completed this year of children aged over 4 years with a recognised learning disability who were reviewed by CDOP between 2021 and 2023. Children with multiple needs often have a long history of health challenges. CDOP strives to understand the child's lived experience and how they communicated their needs. The Child Death Review Team have Improved the quality and detail of information gathered for children with a learning disability. Additional information on vulnerability and deprivation factors are considered as part of the child's review this ensures a more holistic approach to the review of children with multiple needs and has enhanced learning which has been disseminated across the partnership.

We remain grateful to those members of our partner organisations who time after time go out of their way to make the lives of children and their families their absolute priority. And who, despite often challenging circumstances, work above and beyond to give children the experience that they deserve.

Finally, we would like to thank the members of the Child Death Review Team, the Child Death Review Partners, and members of CDOP for their hard work, support, and commitment to the review of all child deaths in Derby and Derbyshire.

Juanita Murray
Chair of the Derby and Derbyshire Child Death Overview Panel
Dr Nic Medd
Designated Doctor for Child Death for Derby and Derbyshire

Derby and Derbyshire Child Death Notifications

Notifications Key Information:

There were 55 child death notifications in 2023/24. This is the lowest number of deaths we've had since 2019.

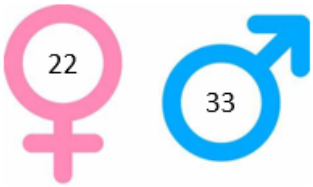
29% received a Joint Agency Response (JAR) as they were sudden & unexpected deaths.

The largest age group was neonatal deaths (0-27 days) at 45.45%. This is slightly above the national average (42.32%). 58% of those were <23 weeks gestation. For all deaths of infants under 1 year old 75% of them had been born prematurely (before 37 weeks).

The largest ethnic group for child deaths was white British (73%).

84% of children died in hospital. Only 34% (16) of those deaths occurred in our local hospitals. Most deaths occurred at tertiary centres close to Derby and Derbyshire with most occurring in Nottinghamshire hospitals.
20% of children die in the Emergency Department. Only 6 deaths occurred in the child's home and 3 were in a hospice.

There does not appear to be a trend of the time of year for child deaths over the last 5 years. This year has seen the lowest number of child deaths in the last 5 years.

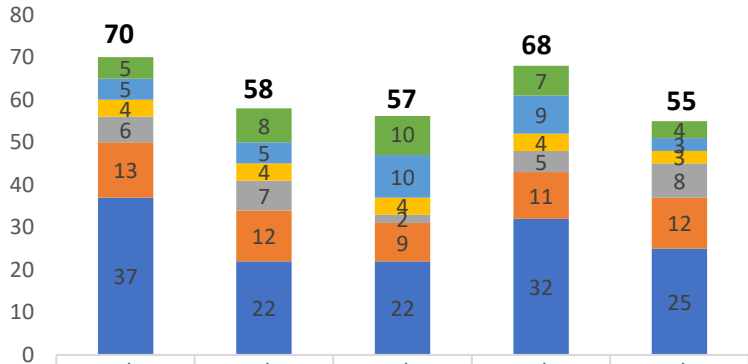


55 notifications received

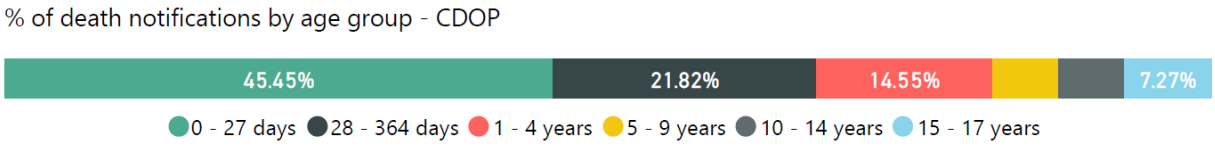
16 Joint Agency Responses completed

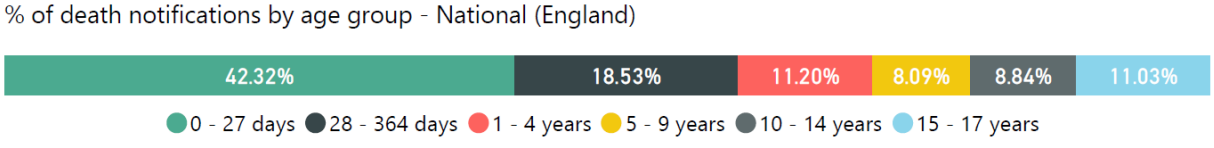
62 average deaths over 5-year period

Number of Child Death Notifications 2019-2024



	19/20	20/21	21/22	22/23	23/24
15-17 years	5	8	10	7	4
10-14 years	5	5	10	9	3
5-9 years	4	4	4	4	3
1-4 years	6	7	2	5	8
28-364 days	13	12	9	11	12
0-27 days	37	22	22	32	25





Derby and Derbyshire CDOP Completed Reviews

68 CDOP reviews completed

66% with modifiable factors (43% England)

12 CDOP meetings held.

CDOP reviews in 23/24 by year of death

Year of Death	Cases
2017/18	2
2018/19	1
2020/21	2
2021/22	11
2022/23	40
2023/24	12

CDOP Review Key Information:

The most frequently recorded categories of death were:

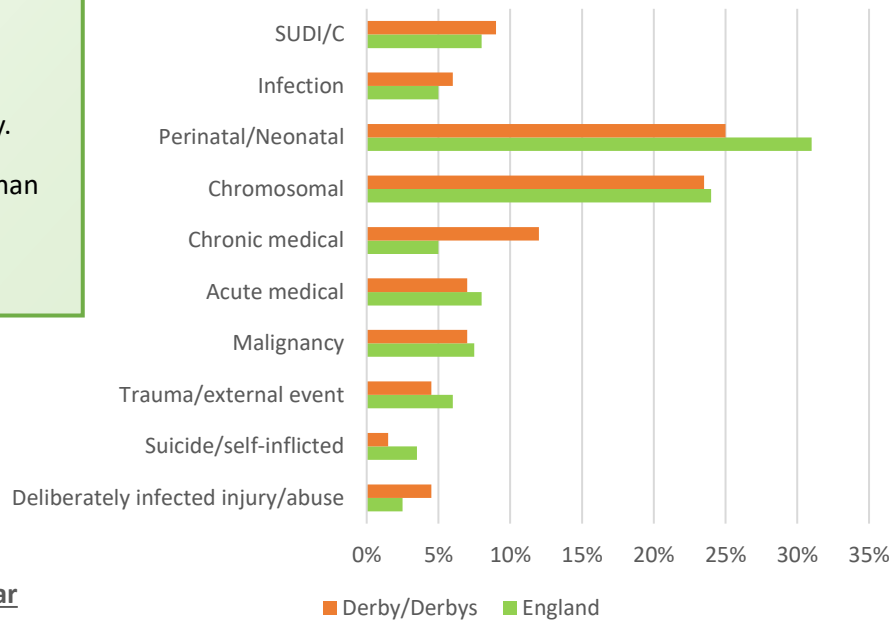
- Deaths due to perinatal/neonatal event (25%).
- Deaths due to chromosomal, genetic or congenital abnormality (24%).
- Deaths due to chronic medical condition (12%).

Nationally, the top 2 categories were also perinatal/neonatal event and chromosomal/genetic/congenital abnormality.

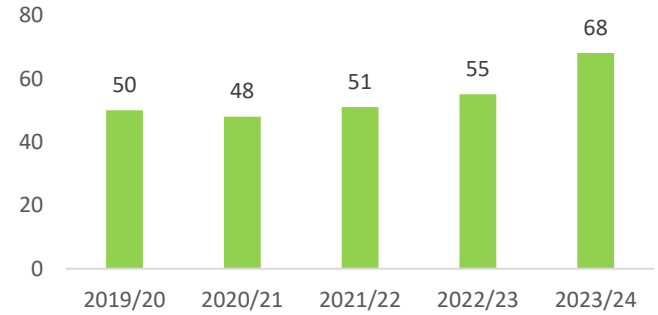
This year CDOP reviewed more child deaths than in the previous 4 years.

Cases are only reviewed at panel once all other investigations (including Inquests, Police investigations, Serious Incident Investigations and Child Safeguarding Practice Reviews) are concluded and reports available to CDOP. This can lead to some delay between the year of death and completion of the review.

Completed CDOP Reviews by Primary Category of death for Derby/Derbyshire and England 2023/24 (data taken from NCMD data release 2024)



CDOP Reviews completed by Year



Derby and Derbyshire Identified Contributory Factors

As part of the child death review process, CDOP records any contributory factors identified during the review and decide which may be modifiable. The factors are recorded in 4 domains and more than one factor can be identified in each child death review. CDOP have a process of scoring any factors identified some of these will be considered a contributory factor.

Top 5 Contributory Factors:

Child health history/medical conditions (A)

Risk factors in mother during pregnancy/delivery (A)

Parent/carers health (B)

Smoking/alcohol/substance misuse by parent/carer (B)

Child's developmental conditions/disabilities (A)

Most common contributory factors identified:

Domain A: factors intrinsic to the child:

- Child health history/medical conditions.
- Risk factors in mother during pregnancy/delivery.
- Child developmental conditions/disabilities.

Domain B: factors in the social environment including family and parenting capacity:

- Parent/carers health
- Smoking/alcohol/substance misuse by parent/carer.
- Household functioning, parenting/supervision.

Domain C: Factors in the physical environment:

- Home safety/conditions
- Vehicle collision
- Sleep environment

Domain D: Factors in service provision:

- Following guidelines/pathway/policy
- Access to appropriate services.
- Initiation of treatment/identification of illness.

Domain	Identified in:
Domain A – child	45 cases (66%)
Domain B – social environment	40 cases (59%)
Domain C – physical environment	16 cases (23%)
Domain D – service provision	22 cases (32%

Derby and Derbyshire Identified Modifiable Factors

CDOP is responsible for identifying any modifiable factors in relation to the child's death. Modifiable factors are defined as factors which, by means of nationally or locally achievable interventions, could be modified to reduce the risk of future child deaths.

Top 5 Modifiable Factors:

Smoking (household, 44% and maternal smoking in pregnancy, 20%)

Guidelines/policies not followed (13%)

Unsafe sleep arrangements (11%)

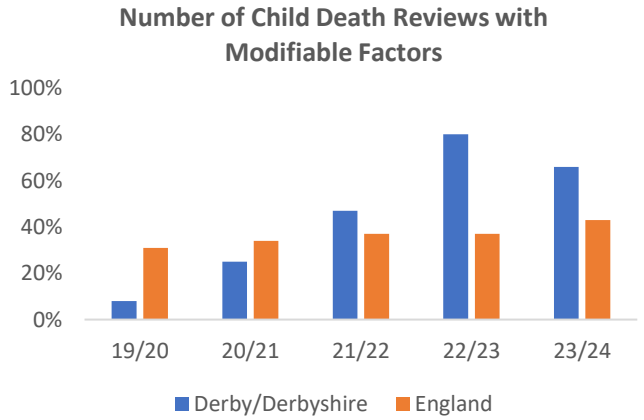
Communication between agencies (11%) and with families (11%)

High maternal BMI (11%)

Modifiable factors key information:

- Modifiable factors were identified in 66% of cases compared to 43% across England.
- Only 2 of the 5 modifiable factors are the same as identified in 2022/23 (unsafe sleep and smoking).
- Deaths categorised as trauma/external factors had the highest percentage of modifiable factors (100%) this is also reflected in the national data (76%).
- The age group 1-4 years had the highest % of modifiable factors overall.
- Most modifiable factors were identified in Domain D: Factors in service provision.

Primary category of death (CDOP)	Modifiable factors identified (%)
Trauma & external factors	100%
Suicide/deliberate self-harm	100%
Sudden unexpected, unexplained death	83%
Acute medial/surgical	80%
Malignancy	80%
Perinatal/neonatal event	76%
Infection	75%
Deliberately inflicted injury, abuse or neglect	67%
Chronic medical condition	50%
Chromosomal, genetic and congenital anomalies	38%
Total	66%



Age group	Modifiable factors identified (%)
0-27 days	65%
28–364 days	83%
1-4 years	88%
5-9 years	40%
10-14 years	44%
15-17 years	64%
Total	66%

The Child Death Review Team work hard to support CDOP in identifying modifiable factors. There are no national guidelines on the interpretation of modifiability for CDOP meetings. The team have produced local guidelines to support decision making and there are often active debates on modifiability within the meetings. The team have recognised that work will need to continue in supporting CDOP to gain the balance between what can be modified from individual cases and what needs to be considered in terms of population health.

Learning Themes – Child Mortality and Deprivation

All child deaths are important to CDOP. We can all learn from individual deaths by sharing positive practice as well as the consideration of improving practice across the partnership. CDOP has a role to look at themes and trends and to focus on any improvements that can be made to prevent future deaths and improve care and services to children.

The focus for the Child Death Review Team this year was to support CDOP and wider partners to have a consistent approach to the identification and understanding of the impact of deprivation and health inequalities on our children and families with the aim of learning from those deaths where deprivation is a factor to support and improve the health and wellbeing of children within Derby and Derbyshire.

The Child Death Review team held a development day specifically to consider some challenging areas for CDOP which included how the team and CDOP consider deprivation and the impact this has on children including their death.

The Assistant Director and Consultant in Public Heath, who are members of the CDOP meeting, shared a presentation on child death and deprivation to support the wider group to consider how CDOP could achieve a consistent approach to deprivation when reviewing children's deaths.

There are 7 domains of deprivation, which combine to create the Index of Multiple Deprivation (IMD2019):

Income *(22.5%)*

Measures the proportion of the population experiencing deprivation relating to low income

Supplementary Indices

Income Deprivation Affecting Children Index (IDACI) measures the proportion of all children aged 0 to 15 living in income deprived families

Income Deprivation Affecting Older People Index (IDAOPI) measures the proportion of those aged 60+ who experience income deprivation

Employment *(22.5%)*

Measures the proportion of the working age population in an area involuntarily excluded from the labour market

Education *(13.5%)*

Measures the lack of attainment and skills in the local population

Health *(13.5%)*

Measures the risk of premature death and the impairment of quality of life through poor physical or mental health

Crime *(9.3%)*

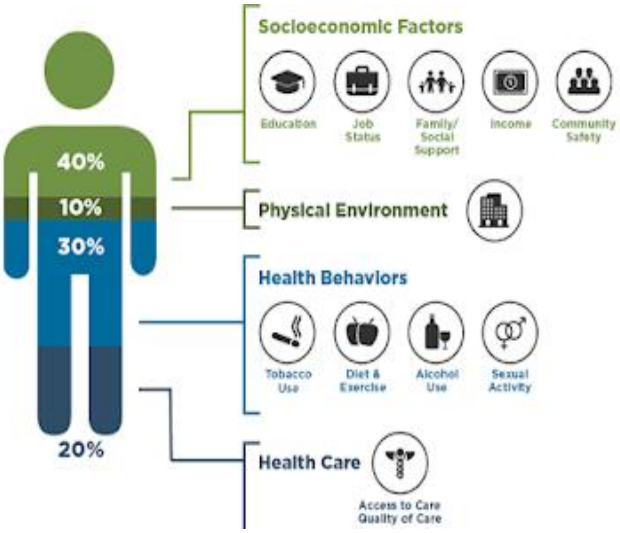
Measures the risk of personal and material victimisation at local level

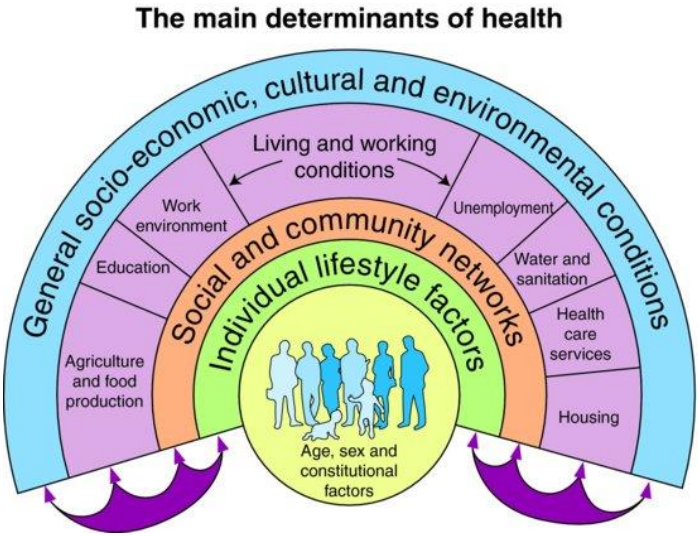
Barriers to Housing & Services *(9.3%)*

Measures the physical and financial accessibility of housing and local services

Living Environment *(9.3%)*

Measures the quality of both the 'indoor' and 'outdoor' local environment





The National Child Mortality Database (NCMD) produced a thematic report on child mortality and deprivation. A key finding was that 'there was a clear association between the risk of death and the level of deprivation for children who died in England between April 2019 and March 2020. This association appeared to exist for all categories of death except malignancy'. Further analysis also suggested that over a fifth of all child deaths might be avoided if children living in the most deprived areas had the same mortality risk as those living in the least deprived. This equates to 700 fewer children dying per year (NCMD 2021)

The DWP in 2021 looked at material deprivation for the bottom and top fifths of the income distribution for children and families.

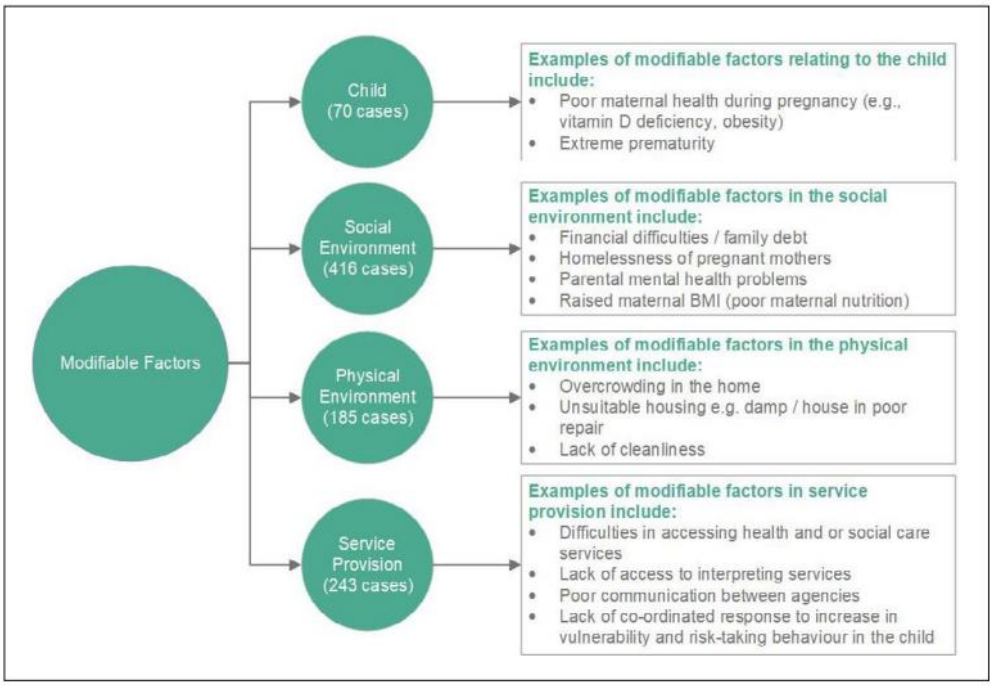
More **children** from the bottom compared to the top 5th:

- Do not have access to outdoor space or facilities to play safely.
- Cannot afford sports equipment or a bicycle.
- Cannot afford to go on a school trip once a term.
- Cannot afford fresh fruit/vegetables daily.

More **parents** in the bottom compared to the top 5th:

- Cannot afford to keep their home warm.
- Cannot keep up to date with their bills.
- Cannot replace broken electrical goods.
- Cannot make savings of £10 per month or more.

Figure 2. Numbers and examples of modifiable factors identified in Cohort 2

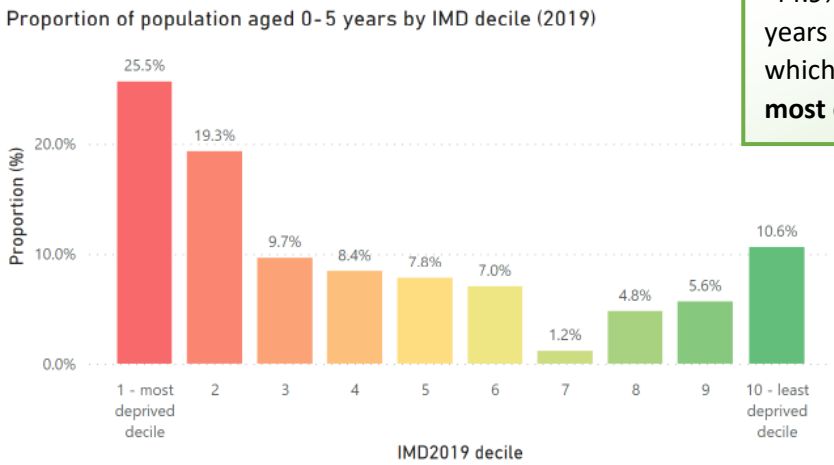


N.B. The number of cases presented in the figure does not sum to total number of cases reported due to some cases having a modifiable factor in more than one category.

Modifiable factors in the **social environment domain** were more common with increasing deprivation (NCMD, 2021).

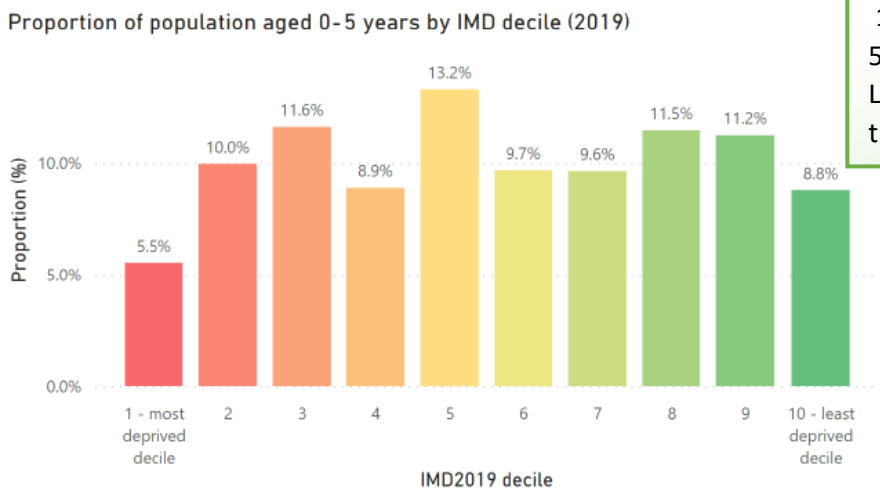
Over a fifth of all child deaths might be avoided if children living in the most deprived areas had the same mortality risk as those living in the least deprived. This translates to over 700 fewer children dying per year.

<u>Deprivation of all children in Derby aged 0-5 years:</u>

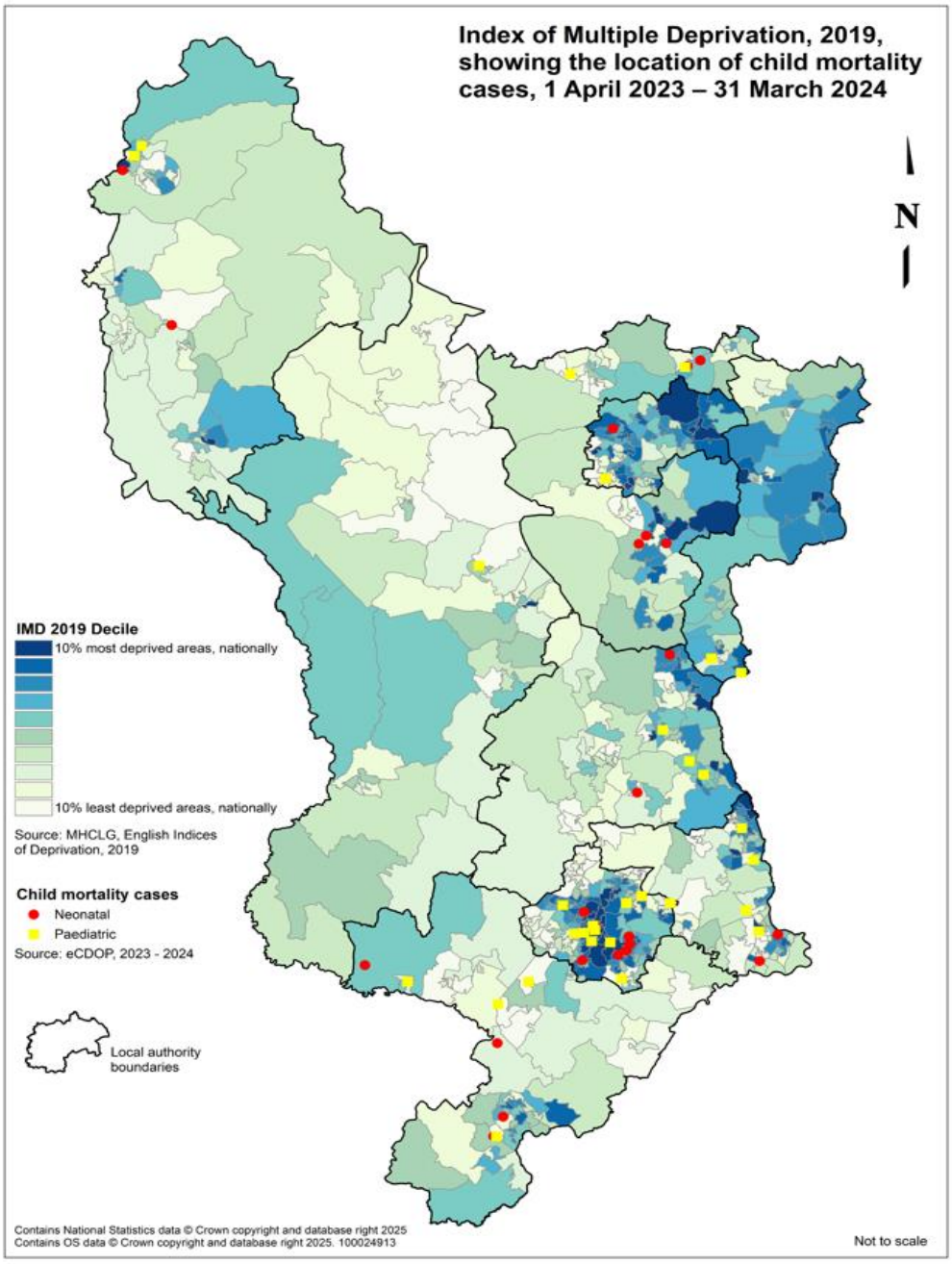


44.9% of children aged 0-5 years in Derby live in LSOAs which are amongst the **20% most deprived** in England

<u>Deprivation of all children in Derbyshire aged 0-5 years:</u>



15.5% of children aged 0-5years in Derbyshire live in LSOAs which are amongst the **20% most deprived** in



CDOP Developments – Identifying and Understanding Deprivation

Derby and Derbyshire child death review team have been proactive during this year in developing a consistent approach to the collection of information on deprivation factors and how CDOP considers these factors as part of the child's review including the identification of contributory and modifiable factors related to deprivation. This work has included:

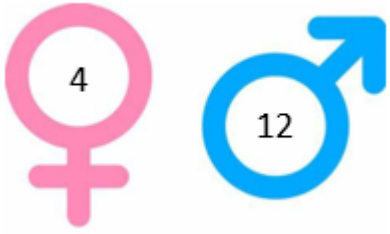
- Requesting additional information about deprivation factors on the reporting forms
- Engaging with education to request information for the child's review.
- Raising awareness regarding deprivation through a CDOP newsletter.
- Active consideration in the CDOP meetings of deprivation factors and what this meant for the child and family.
- Consideration of deprivation factors as modifiable factors as appropriate

The developments in improving the quality of information on deprivation factors shared with the child death review team is ongoing. The CDOP meeting will continue to work proactively in achieving consistency when considering the contributory and modifiability of deprivation factors.

Learning Themes – Children with a Learning Disability

An audit was completed this year of children aged over 4 years with a recognised learning disability who were reviewed by CDOP between 2021 and 2023.

Year of CDOP Review	Number of LD Cases Reviewed
2021	6
2022	6
2023	4
Total	**16**



CDOP Review Key Information:

- Only 3 of the children died at home or in a hospice. Most of the children died either on PICU (5) or ED (5).
- 38% received a Joint Agency Response and multi-agency investigation into the causes of death.
- 56% were referred to the coroner for investigation.

Cause of the learning disability/neurodisability:

- 50% of children had a predisposing genetic condition where a LD was part of the condition.
- 31% were born prematurely or suffered Neonatal HIE (hypoxic ischaemic encephalopathy).

Most of the children had complex needs and comorbidities and all the children had communication difficulties.

The children's needs included:

- Epilepsy
- Frequent infections
- Visual and hearing impairment
- Being artificially fed

Cause of death

- Most children died of an acute illness and due to their complex needs this made the children more susceptible to infection and illness.
- 75% (12) of the children reviewed died of a lower respiratory tract infection.

Contributory and modifiable factors

- 75% of children had been in contact with children's services. Many being a Child in Need at the time of their death this was usually due to the nature of their complex needs and the support required from children's social care.
- There is a known link between children suffering abuse and neglect who are disabled or have significant needs, 25% of this cohort had child protection investigations at some time in their life and 19% were Children in Care.
- Parental mental health difficulties were identified in 63% of the family's, this highlighted some of the challenges in caring for a child with complex needs.
- Domestic abuse was reported in 44% of families.
- Modifiable factors were identified in 9 of the 16 cases (56%) which included household smoking at 38%, families being on the waiting list for house adaptations at 31% and financial deprivation.

Children with multiple needs often have a long history of health challenges. CDOP strives to understand the child's lived experience and how they communicated their needs.

CDOP Learning – Domain A – Factors intrinsic to the child.

- Respiratory illness is the biggest cause of death.
- Ensuring optimal growth and nutrition is vital to reducing incidence of infection. However, feeding can be challenging for these children.
- Boys are especially vulnerable (75% deaths in this group)
- Death can be sudden but expected. A greater understanding amongst professionals would support early decision making with the lead health care professional to ensure an appropriate multi-agency response.
- Understanding the voice of the child - complex needs and reduced communication impact on detecting symptoms early.
- The importance of Advanced Care Plans which are regularly reviewed and updated and should be visible across the system including the ambulance service and Emergency Department.

CDOP Learning – Domain B- Factors in social environment including family and parenting capacity.

- The importance of considering and responding to vulnerabilities within the home and family environment.
- Smoking cessation referrals should be made if children are exposed to household smoking.
- Financial deprivation – families should have appropriate financial support and be supported by professionals to achieve this.
- Ensure specialist equipment needs are met including appropriate training for parents and any carers of the child.

CDOP Learning – Domain C – Factors in the physical environment.

- Delays in housing adaptation or new housing impacted on health needs increasing vulnerability and safety issues for children and families.
- Access to specialist equipment.

CDOP Learning – Domain D – Factors in service provision.

- The importance of Identifying the lead health professional and key worker for a child. This can be challenging especially if there are multiple professionals involved with the family.
- Effective communication between agencies and services. Regular multi-disciplinary team meetings to ensure a coordinated plan for the child and family.
- Children's social care support should be considered for children with complex needs.
- Assessment of risk and vulnerabilities including the use of tools such as the Graded Care Profile if neglect is a concern.
- Health professionals to be aware of diagnostic overshadowing where symptoms are attributed to an individual's disability leading to a delay in diagnosis or treatment.
- Complex needs impact on the ability to access services including attending appointments and reviews in primary and secondary care settings.
- Lack of 24/7 community nursing support to enable children to die at home instead of in hospital or hospice.
- Some challenges with access to education provision due to the complex health care needs for some children.
- GP annual health checks should occur from 14 years and children should be on the Learning Disability register at GP surgeries.

National Learning

The NCMD published a report; Learning from deaths: Children with a learning disability and autistic children aged 4-17 years. (NCMD 2024)

The report looked at deaths over a 3 - year period between April 2019 and March 2022. Many of the learning themes mirrored the themes in Derby and Derbyshire

Actions by the Child Death Review Team

- Improvements in the quality and detail of information gathered for children with a learning disability, this now includes requesting information from additional sources such as the community nursing teams and special schools.
- The team request additional information on vulnerability and deprivation factors and have adapted the child death review meeting forms to capture these factors to support the CDOP review.
- CDOP are asked to specifically consider how children with a learning disability communicate and to consider the lived experience of the child.

Future considerations

The audit findings and learning has been shared at a training day: A Multi-Disciplinary Team approach to preventing early deaths in young people with learning disability (Disability Steering Group) and will be shared with the LeDeR Team.

Keeping Babies Safe in Derby & Derbyshire

The Keeping Babies Safe Strategy – the Three Steps for Baby Safety was published in 2021 and underpins the work this year around the number one priority of Derby and Derbyshire Safeguarding Partnership – The Safety of Babies.

The Derby and Derbyshire Safeguarding Childrens Partnership (DDSCP) recognised that there was a wealth of learning and recommendations following child safeguarding practice reviews, child death reviews and by auditing practice. The KBS strategy became the blueprint to develop practice however it was clear that practitioners needed support, guidance, and training to really make a difference to families and their babies. The DDSCP and the keeping babies safe steering group led the way in the development of initiatives, tools and resources that would provide a consistent approach to the messages shared with families whilst meeting a diverse population and considering the many different practitioners across the multi-agency partnership.

Keeping Babies Safe Champions

The KBS Champions have had a key role in developing the KBS resources, ensuring that the key safety messages are shared amongst practitioners and have been inventive in how they are shared with parents and families.

There are approximately 100 KBS Champions across Derby and Derbyshire. A network event is delivered to champions twice a year. These meetings provide an opportunity to update champions on KBS work across the system and allow practitioners to share their experiences. The meetings are well attended and receive positive evaluations.

The role of the KBS Champion is to:

- Support practitioners within a service/team to have a good knowledge and understanding of safer sleep practice, safe handling and home safety
- Support and encourage practitioners to confidently deliver clear consistent messages to parents and carers
- Enable practitioners to recognise that some families may have additional vulnerabilities and require extra support to understand the messages and to make the right choices for their baby's safety
- Be a point of contact for colleagues to offer advice/signposting in relation to baby safety
- Support practitioners to keep up to date with key safety messages
- Disseminate any new information or resources across a service/team

A full evaluation of the practice and outcomes of the KBS initiatives was completed by the strategic lead for KBS on behalf of the DDSCP. Evaluation and Impact Report on Three Steps for Baby Safety sets out progress that has been made locally. This including gaining the views of families, frontline practitioners, and leaders. The report is published on the DDSCP website. Recommendations were made for the Keeping Babies Safe Steering group to consider and action appropriately. There has been real enthusiasm, some say a 'buzz' around the KBS work. Practitioners and leaders have been committed to helping families make the right choices for their baby particularly vulnerable families. The KBS work will continue and the aim that the KBS tools and resources become further embedded across the Derby and Derbyshire multi-agency partnership and babies are protected from abuse and harm.

The Voices of Parents and the child

When a child dies it is a tragedy for any family no matter what the circumstances are. Families and individuals manage the death of a child in their own way. Some will want to have an understanding about the child death review process and want to contribute their thoughts and feelings about their child's care and share personal information about their child, others want to grieve in their own way and do not wish to contribute the processes following the death.

It is important to the Derby and Derbyshire Child Death Review Team that we contact every family following the death of their child and encourage a dialogue and the sharing of information if that is what a family wish to do. This is very much in the hands of the family. The team respect the wishes of families and their decisions.

The CDOP meeting will always consider the voice of the child and if the family have shared any views or information or would like any feedback following CDOP meeting.

The Lead Nurse for Child Death Review is a link for the families regarding the child death review processes. This includes liaising with the Coroner around care concerns, signposting families to support and bereavement services and answering any questions regarding the CDOP processes and meetings.

Any family requesting feedback will receive a letter from the Chair of CDOP thanking them for their contribution and with any learning that has been gained from hearing their child's story.

The team and CDOP believe it is important to get the balance between an independent review of a child's death and remembering the importance of the child's life and voice and how this can enrich any learning for CDOP and our wider partnership.

Assurance

To ensure that CDOP is meeting the statutory guidance (2018) it is important to give assurance to the Child Death Review Partners (CDR) that CDOP is functioning well and is sharing and disseminating the learning across the partnership. This is achieved by quarterly reporting by the Chair of CDOP to the CDR partners and by sharing any areas of developments as well as any risks or concerns. Assurance is also given through the Derby and Derbyshire ICB Safeguarding Committee and through the sharing of the Annual Report to the CDR Partners and the Derby and Derbyshire Safeguarding Children's Partnership. The report is then published on the DDSCP website.

The dissemination and sharing of learning are fundamental to the work of the Child Death Review Team and CDOP. The team disseminate leaning through other groups such as JUCD Childrens Delivery Board, the Derbyshire Self-harm and Suicide Prevention Partnership and the Derby and Derbyshire Safeguarding Childrens Partnership. The team share learning regionally with the East Midlands Regional CDOP group and nationally with NHSE and the NCMD.

Achievements of the Child Death Review Team and CDOP

- Focused on deprivation and the impact on child death by exploring the use of deprivation tools with Public Health colleagues to support a better understanding of the vulnerability of families as part of the CDOP review.
- Produced a researched based Neonatal Report from the learning identified in CDOP to be shared with partners, providers, and the Local Maternity and Neonatal System Board.
- Monitored the numbers of neonatal deaths in comparison to the national average.
- Completed an audit of children who have died with a learning disability.
- Completed a briefing for practitioners on working with families from the travelling communities.
- Planned and delivered a Development Day for CDOP members, the mortality leads and bereavement nurses with a focus on deprivation and ethical considerations in child death.
- Developed an alternative method of case presentation to be used when reviewing cases of inflicted causes of death to enable CDOP to focus on the learning and ensure sensitive and emotional support for panel members.
- Continued to monitor the progress of the commissioning of community palliative care services for children.

Key Priorities for 2024-2025

- Develop a psychological support package for CDOP members and the child death review team to enable reflection and support when listening and dealing with the sensitive and distressing nature of child death.
- Review local guidance on modifiable factors
- Review the guidelines for the Joint Agency Response (JAR)
- Plan a webinar to raise awareness and launch the new JAR guideline and processes
- Plan further JAR training
- Feedback from CDOP members on the sharing and dissemination of learning
- Development of a formal governance structure with the Child Death Review Partners
- Continued development of the work on deprivation and the association with child death.
- Continue to monitor and report on the lack of palliative care in the community to allow children to die at home.
- Complete an audit of the impact of safer sleep advice and the parent education programme 'Never Ever Shake Your Baby'.
- Review of the KBS Strategy 'The Three Steps for Baby Safety'
- Develop and deliver Keeping Baby's Safe Roadshows for Early Years Practitioners

References

Child death data release 2024 | National Child Mortality Database

Households below average income (HBAI) (DWP 2021)

Infographic The English Indices of Deprivation (2019) Ministry of Housing Communities and Local Government

Joined Up Care Derbyshire (JUCD) Start Well Dashboard

keeping-babies-safe-strategy-v2-final-nov-24.pdf

NCMD-Child-Mortality-and-Social-Deprivation-report_20210513.pdf

NCMD-Learning-disability-and-autism-report_FINAL.pdf

Public Health Deprivation Presentation for CDOP Development Day

The Dahlgren and Whitehead model of the main determinants of health (1993)