Leicester, Leicestershire and Rutland Annual Report (2015/2016)

CDOP 2016

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Leicester, Leicestershire and Rutland
Child Death Overview Panel Annual Report 2015/16

Introduction

As the new Chair of the LLR Child Death Overview Panel it is my pleasure to introduce the Annual Report for 2015/16. During this period the Panel was Chaired by Jasmine Murphy, Consultant in Public Health at Leicester City Council and I would like to express my thanks to her on behalf of all the Panel for the work she undertook and leadership she showed in ensuring the Panel effectively and robustly reviewed all deaths of children normally resident in the area. We wish her luck in her new role with Public Health England.

The role of CDOP can be difficult, complex, upsetting, as well as rewarding. The child death overview process is not an investigation and does not supersede the need for organisations to undertake their own reviews following the death of a child. However it is an opportunity to undertake a systematic review of all the information available concerning the death, and to identify whether there were any modifiable factors. The Panel then identifies and advocates for needed changes in legislation, policy and practices, or public awareness, to promote child health and safety and to prevent future child deaths. An example of this is the continued work to highlight the dangers of lithium 'button' batteries, following cases reviewed by CDOPs where young children had died following catastrophic bleeding as a result of the electric charge from the batteries after they had been swallowed. The resulting local awareness raising activities led by CDOP and supported by all partners has now been supplemented by national work and campaigns including Public Health England, ROSPA (Royal Society for the Prevention of Accidents) and other national charities and campaign organisations.

Finally I would like to thank all the Panel members and staff working on behalf of CDOP, and in particular Lisa Hydes the Child Death Review Manager whose tireless work and dedication ensures children and families have a real voice in contributing to our efforts to reduce these tragic deaths in the future.

Core Functions of the Child Death Overview Panel

The Children Act (2004) placed a statutory duty on local authorities in England to set up LSCBs. One of the duties of the LSCB is to ensure a review is undertaken on the deaths of all children who are normally resident within their area. The child death overview process has been established within LLR since February 2009.

The remit of the child death overview process is to co-ordinate a systematic review of the death of children between 0 and 18 years of age (the review does not include stillbirths).

The process incorporates two interrelated pathways that allow for expected and unexpected deaths to be reviewed, the purpose of which allow for;

"(a) collecting and analysing information about each death with a view to identifying-

-any case giving rise to the need for a review mentioned in Regulation 5(1) (e);

-any matters of concern affecting the safety and welfare of children in the area of the authority; and

-any wider public health or safety concerns arising from a particular death or from a pattern of deaths in that area;

(b) putting in place procedures for ensuring that there is a coordinated response by the authority, their Board partners and other relevant persons to an unexpected death."

The child death overview process does not supersede the need for organisations to undertake their own reviews following the death of a child.

It is intended that the child death overview process will incorporate issues identified within the Serious Case Review (SCR) process and any alternative review processes in order to ensure shared learning.

The remit of CDOP panels nationally is to provide an overview of cases and identify learning that seeks to reduce future deaths and as such views the 'wider picture'. It is not the intention of CDOP panels to identify a list of failings or review the cases under the same criteria as that considered during an SCR process. Therefore in the majority of cases it is acknowledged that there will be no recommendations to be made by CDOP. This does not mean that significant work has not been undertaken in assuring that all cases are reviewed appropriately. It is important to note that even in cases where specific recommendations or learning is noted and acted upon, from a statistical viewpoint it is almost impossible (due to the low numbers involved) to demonstrate a direct correlation between action undertaken as a result of a recommendation from CDOP and a decrease in the number of deaths in a particular category year on year.

As part of the review of all of the cases, the panel monitors the appropriateness of the professionals' responses to each child death to ensure thorough consideration of how such deaths might be prevented in the future. It also monitors the support and assessment of services offered to the families of children who have died.

Alongside determining if modifiable factors can be identified within a case, CDOP members are also asked to consider if there are additional actions, learning points or recommendations that can be drawn from the review. The panel seeks to help identify and report on any public health issues that may pose risks to children's health or development. In order to ensure learning is identified themed areas of work are undertaken throughout the year. Cases that have already been reviewed will be reviewed alongside new cases with similar contributory factors. As part of this work the CDR Manager along with public health professionals look at current CDOP cases and seek to establish if/how they mirror the national picture. Following discussions at CDOP panel it was been agreed that a report would be produced reviewing the data that CDOP has attained over the past 6 years with a view to providing a more detailed comparative analysis of the data and findings made at panel; this has been completed and presented to both LSCBs and work continues based on the findings of this report.

Child Death Review Process

Accountability and Assurance

LLR CDOP is a sub group of the LSCB and as such is accountable to the Independent Chairs of the respective LSCBs. Accountability is assured in a number of ways:

- Under current arrangements the CDR Manager is an officer of the respective LSCBs. Reports are submitted to the Boards (in consultation with the CDOP Chair) at agreed timescales to provide assurance in relation to the effectiveness of the work of the panel.

- The DfE requires LSCBs to provide annual data in relation to the number of notifications their respective child death overview panels receive. For LLR this data is provided on behalf of the respective LSCBs by the CDR Manager.

- As part of the accountability and assurance offered by CDOP, the CDR Manager attends the SCR Subgroups for both Leicester City and Leicestershire and Rutland on a monthly basis to ensure there is early notification of cases and effective sharing of information. Under current arrangements CDOP will not undertake a review until the SCR or alternative reviews has been completed.

  Note: *For all cases that may be subject to an alternative parallel review the CDR Manager provides a briefing to panel outlining the facts of the case. A monthly update regarding progress will then be made*.

- Close links remain with both HM Coroners with jurisdiction within LLR in order to ensure there is an agreed process for mutual sharing of information. Enabling information to be shared proportionally and appropriately in order to provide a fuller understanding of the factors associated with child deaths.

- During 2013 it was agreed, with representatives from the commissioning body for CDOP, that the reports compiled by the named nurses following a home visit would be reviewed by commissioners (on a 3 monthly basis). Following an initial pilot to assess the feasibility of this, the CDR Manager meets with an identified Designated Lead to review and audit the reports and identify any key areas to address.

Panel membership

The Chairing of the CDOP panel has recently changed and is now chaired by Rob Howard, Consultant in Public Health (from September 2016). Prior to this the Chair was Dr Jasmine Murphy, Consultant in Public Health. The current chairing arrangement is supported by both LSCBs.

CDOP has a permanent core membership of the appropriate level of seniority, including public health, child health, police and social care. 'Working Together to Safeguard Children 2015' is not prescriptive regarding the composition of panel members. In order to assure appropriate representation is maintained at panel, the membership of the LLR CDOP panel is reviewed on an annual basis and a record of attendance at panel is logged. The current membership is being reviewed (October 2016) and any amendments will be reflected within the revised terms of reference

Current membership of the panel can be found in the CDOP Terms of Reference on the LSCB websites.

CDOP currently meets at least 6 weekly for 3 hours per panel. At the beginning of each meeting panel members are reminded of the need to observe confidentiality with regard to the information they review.

Case Review Process

Procedures

Currently all child deaths are reported to the CDR Manager. As the designated person to whom child death notifications are forwarded the CDR Manager's name and email address is held by the DfE, who coordinate a national contact list. A notification can be made to the CDR Manager by any professional involved in the care of the child.

As outlined in of 'Working Together to Safeguard Children 2015' registry offices are required to provide a weekly report to CDOP on deaths they are aware of.
These reports ensure that information is received (on behalf of the LSCB by the designated professional) no later than 7 days from the date of registration of death.

The CDR Manager reports to the LSCB all circumstances where abuse has been identified as, or suspected to be, a factor in the death of a child. Where appropriate CDOP will recommend consideration of an SCR.

For cases undergoing criminal review there is a single point of contact identified within the Police to provide information to be presented to panel.

'Working Together to Safeguard Children 2015' provides guidance for LSCBs in regard to timescales for reviewing deaths. For unexpected cases 'Working Together' suggests a timescale of 6 months for the case to reach the phase 3 (final case discussion) stages.

Locally it has been agreed with all partner agencies that:

- Expected cases will be ready for panel within 12 weeks.
- Unexpected cases will be ready for panel within 26 weeks. This time period is guided by the time taken for post mortem results to be made available to the CDR Manager. This is a process which is reflected nationally. The current arrangement of awaiting the results of the post mortem before presenting a case to panel has been agreed within LLR by all panel members.
- All neonatal cases will be reviewed by the Perinatal Mortality Review (PMR) Group prior to being heard at the CDOP. To provide congruency between the two processes the CDR Manager attends the PMR meetings. This process was instigated following close liaison with UHL and continues to be supported by panel members as a means of providing a robust approach to the review of such cases.

Sudden Unexpected Death in Childhood (SUDIC) arrangements

Following local consultation with partners the 'rapid response' process that was referred to within 'Working Together to Safeguard Children 2010' (and remains within 'Working Together to Safeguard Children 2015') is termed locally as the SUDIC response. This outlines the response that is initiated following the sudden/unexpected death of a child.

All notifications are received by the CDR Manager whose role it is to coordinate the initial SUDIC response. The work of the CDR Manager is supported by the project support officer for the CDOP process.

Under the current arrangements the CDR Manager is an officer of the LSCB and the post is hosted within Leicestershire Partnership Trust (LPT). LPT also host the project support officer post.

The current service specification is under revision and this is being led by the Leicestershire and Rutland Safeguarding Children Board (via the Local Authority) on behalf of both Boards. The new arrangements will ensure the agreement is held with the Local Authority and LPT.

As part of the SUDIC response a home visit is considered. Within LLR this function is undertaken by a member of the named nurse safeguarding team (as part of their full time employment within LPT). Where possible this visit will coincide with visits that are being undertaken by the police, in an attempt to provide minimal intrusion to the family. The nurses provide cover during office hours 9am – 5pm Monday to Friday (excluding bank holidays). During 2016 there were a number of changes within the named nurse work force and at present there are 4 nurses providing cover for the rota (2 additional nurses have been recruited to the team and will join the rota over the next 12 months). It has been agreed that as part of the development of the named nurse team, each family will be allocated a nurse who will act as a contact point for the family until the case is reviewed at panel. This will help to ensure bereavement needs of the family are identified and supported and that they are able to contribute to the CDOP process if they wish.

The Designated Doctor (Dr) for unexpected deaths role is covered by one community paediatrician. As part of their remit they are available to provide medical advice in relation to notifications received, chair any initial meetings to discuss the case and chair the final case discussion; they will then present the case at panel. This arrangement is reviewed as part of the doctor's job plan on an annual basis in order to ensure services are being utilised effectively. Cover by the Designated Dr is currently provided on:

- Monday/Tuesday/Wednesday – AM
- Thursday – PM

In addition, in order to aid with the notification process, promote the CDOP process and facilitate the prompt obtaining of information, UHL have a (0.5WTE) specialist nurse located within their Safeguarding Team.

Data analysis providing local picture

Child death data – cases notified to LLR CDOP **during** 1st April 2015 – 31st March 2016

(nb those greyed out will not be reviewed by CDOP)

Notifications received	Unexpected	Expected	Neonatal	Out of Area	Under 23 weeks gestation
84	17	13	30	24	0

In 2015/2016 LLR CDOP held 11 panels and reviewed a total of 102 cases (these will include cases that were notified to CDOP outside of 2015/2016 time period)

Of those cases reviewed, modifiable factors were identified in 20 cases

Modifiable factors were identified in the following areas	
Access to health care Where English was not the first language there had been a delay in contacting the emergency services (this had not had not influenced the final outcome in any of the cases discusses	CDOP undertook a number of areas of work including; o Liaison with the 999 services o Escalation to the LSCB o Awareness raising This was also escalated to the Department for Education for further guidance regarding a national perspective (no response was received)
Neonates transferred between 3 sites in order to receive appropriate assessment and care	o Chief executive contacted (by CDOP) for assurance as to how this is to be managed moving forward with new proposed hospital developments
Smoking by mother in pregnancy **Smoking by parent/carer**	These 2 areas form key components within the LLR Reducing Infant Mortality Strategy
Consanguinity	CDOP has enlisted a public health registrar to undertake a review of current data/literature in order to advise on next steps
Poor communication with families	CDR manager has liaised with partners in order to strengthen communication with families
Medical intervention	Where areas for improvement have been noted; o Policies and protocols have been revised o Feedback to professionals has been provided o Processes to be audited

Learning and dissemination from cases reviewed 2015/2016	
Area	**Action/Learning**
Resources	Coroner issued a regulation 28 with regard to escalation policies (in ensuring concerns are progressed timely and robustly). Employed more obstetricians and cross cover over sites (undertake hot weeks). In addition there has been additional feedback to staff regarding; • Importance of utilizing the emergency buzzer to summon assistance • Review of guidance for the management of the 2nd stage of labour • Review of the escalation policy (ensuring appropriate seniors are aware) – this will be tested annually in order to ensure robustness • 2 additional consultant posts have been advertised (this will also involve a review of jobs plan in respect of cover to be provided)
End of Life Care (and choices)	Recognition of need to support siblings. Families and children supported with regard to their choices for where they wished to be taken care of.
Feedback from families	Feedback to partners regarding how they contacted the family following the death. Feedback to CDOP regarding how contact with families is instigated. Process has been amended as a result. Close liaison with the Coroner's office to provide assurance with regard to the management of the inquest and media involvement.
Processes	CDOP received notification as expected instead of unexpected: • UHL link liaises regularly with ward areas re process to undertake for notification • Ward areas invited to attend multi-agency training hosted by CDOP Head of school unsure of process that occurs for when the death of a child: • Support offered to school • CDOP have established peer support processes to allow schools to offer support to other school who have experienced a death of a pupil
Support for professionals	Support had been offered by HR and by the line manager however the professional has felt unable to return to work and has sought alternative employment. Recognition of professionals personal experiences; • They had also lost a child (and felt that this made offering to the family additionally challenging; they had not shard this with their manager until CDOP spoke with them).
Protocols	Following review at regional meeting professionals highlighted that current protocol for treatment can cause significant complications and will need to ensure this forms key part of planning for future patients

Work Programme 2015/16

- CDOP continued to support the work of the LLR suicide audit prevention group. CDR Manager is a member of the suicide audit prevention group and continues to liaise over relevant areas.

- CDOP has continued to develop and strengthen the role of the named nurse in ensuring families and professionals are supported following the death of a child. The named nurses are allocated families and asked to maintain contact until the case is reviewed at panel in order to facilitate support and allow families the opportunity to participate within the CDOP review.

- The CDR Manager attends (and is vice chair) of the regional CDOP forum. This allows the exchange of information and wider dissemination of learning activities in each locality.

- A National Confidential Inquiry into Suicide and Homicide is to be undertaken. LSCBs will be contacted for information. Ethics approval has been sought. CDR Managers have asked that they are also included in any correspondence.

- CDOP has worked to strengthen and maintain links with partners to ensure shared learning, in particular the utilising the findings of CDOP to enhance work being undertaken to develop an LLR Infant Mortality Strategy. The action plan for this strategy will be built into the CDOP work programme for 2016/17. This includes the emerging evidence from the EMBRACE study on perinatal mortality that highlight maternal obesity as a significant risk factor.

- In January 2016 CDOP produced a Supplementary Report which provides an analysis of data from 2009/10 to 2014/15. LLR CDOP has been in existence since 2009 and child deaths have remained relatively constant over this time period. This supplementary report took a 6 year snapshot across LLR to evaluate CDOP data in more detail. This allowed for pooling of the datasets to enable a more robust analysis of any relationship between child deaths and risk factors such as smoking, deprivation and ethnicity. It also allowed benchmarking against England and highlighted areas requiring further action to reduce child deaths.

The key findings of the report included:

362 reviews completed by LLR CDOP

- *Leicester City: 204 (56.4%)*
- *Leicestershire County: 149 (41.2%)*
- *Rutland County: 9 (2.5%)*

22% of all child death reviews for LLR were identified as having modifiable factors.

- *Leicester City: 11%*
- *Leicestershire County and Rutland: 11%*

25% of all child deaths reviewed across LLR were due to chromosomal, genetic or congenital anomalies. A separate breakdown for Leicester and LR is not available as data was not segregated prior to 2013/14.

45% of all child deaths across LLR occurred within the first year of life.

Recommendations were:

1. There is evidence of a disproportionate number of child deaths in the more deprived Quintiles. All partners should assess the work currently in place to target vulnerable groups and develop an action plan to identify how the number of deaths can be reduced.
2. It is a consistent feature both locally and nationally that children under the age of 1 account for the majority of child deaths. These deaths have common features which include low birth weight, prematurity and maternal smoking and associated issues of hypertension, diabetes and obesity and their links to poverty and infant nutrition. Given that year on year the percentage of deaths remains high, all partners should ensure that appropriate action plans are in place to address the areas identified.
3. A community engagement exercise should be commissioned to explore certain ethnic Groups' views on consanguinity and access to universal and specialist services.
4. The proportion of child deaths aged 1-4 years is significantly higher than the national average: CDOP should undertake further analyses on this in order to inform partners' action plans.
5. The rate per 100,000 of child deaths for Pakistani children is significantly higher than the LLR average: CDOP should undertake further analyses on this in order to inform partners' action plans.
6. CDOP should develop a tool to standardise decision making on categorisation of modifiable factors in all cases reviewed.
7. CDOP should provide assurance to the LSCBs on its action plan to improve the rate of completed reviews.
8. Further supplementary reports should be undertaken, pooling data as appropriate in order to look closely at trend, with this report providing a baseline.

A number of these recommendations were therefore built into the CDOP work programme for 2016/17.

Conclusion and Recommendations

During 2015/16 the Child Death Overview Panel reviewed 102 cases and found that 20 of them had modifiable factors that 'may have contributed to the death of the child and which, by means of locally or nationally achievable interventions, could be modified to reduce the risk of future child deaths'. This represents a significant potential for reducing these deaths in the future.

The key recommendations following this Annual Report and the Supplementary 6 year review are therefore:

1. CDOP should continue to develop a robust approach to;
    - Interpreting the data produced both locally and nationally to identifying potential areas where action should be taken
    - Understanding the evidence around what works to reduce modifiable risk factors
    - Promoting cost effective interventions which enable real change – in behaviour, knowledge, processes or systems, to reduce the risk of preventable childhood deaths.
2. Undertake a literature review and develop potential approaches to reduce the number of childhood deaths associated with consanguineous marriages as a result of recessive gene disorders
3. Undertake a Health Needs Assessment on Maternal Obesity and Perinatal Mortality including a literature review of international and national approaches to increase awareness and reduce risks; and a review of current services.
4. Further analysis of the 6 year review, adding the data from 2015/16 and analysing the higher than expected proportion of deaths in the 1-4 year old age group.
5. Work with CDOPs across the region to continue to share good practice and to examine potential for combining data to allow more robust sub-group analysis of risk factors
6. Support the Learning Disabilities Mortality Review Programme (LeDeR) - a focused review of cases where the deceased person was known to have a learning disability