



## **Rapid Resolution and Redress**

### **Sands response to the Department of Health (England) consultation**

#### **May 2017**

#### **About Sands**

Sands is the stillbirth and neonatal death charity. We work to reduce the number of babies dying and to improve care and support for anyone affected by the death of a baby.

The charity was formed 40 years ago by bereaved parents who felt isolated in coping with the devastation of their baby's death. Using the experiences of the thousands of families who contact us, Sands has changed the culture and delivery of bereavement services. Sands have more than 100 support groups which, along with the national helpline, offer direct support throughout the UK.

In the last decade we have campaigned for perinatal mortality reduction. Working with government departments and maternity care stakeholders in all four UK countries we have focussed national attention on this previously neglected area, and we contribute to a range of reduction initiatives. National targets to reduce perinatal deaths are now in place in England and Scotland, and included in Labour and Conservative party manifestos for the 2017 general election. We aim to bring the voice and experience of bereaved families to inform work to tackle the high proportion of perinatal deaths that are potentially avoidable.

#### **The need for lesson learning**

Sands has called for better investigations when any baby dies, since 2011. We know from confidential enquiries dating back to the 1990s and recently in 2015 that poor care contributes to deaths at term in 60% of antepartum stillbirths<sup>i</sup>, and current enquiries are likely to find similar or higher figure for intrapartum-related harm. Yet too many baby's deaths are not investigated robustly and lessons to improve future care are lost. For over a third of cases when a term baby suffered harm in labour the local review of the care was of poor quality<sup>ii</sup>. The same mistakes carry on being repeated.

Parents are left without answers about why things went wrong. When they suspect poor care played a part but is being hidden, they have few effective channels to find answers. A recent survey conducted by Sands showed that most parents just want to find out what happened and to minimise the risk of future tragedies. Very few seek financial benefits. Bereaved parents turn to litigation when it appears to be the only way to get answers and because it ensures an external and independent review of their case.

Sands' evidence to the Public Administration Select Committee enquiry into the complaints system showed that parents find it highly unsatisfactory, saying it is drawn out, complex, unresponsive, patronising and distressing. Parents who feel forced to take this route have a very strong interest in a litigation scheme which takes account of their voice, identifies learning, and minimises their stress.

In 2016 Sands contributed to the NHS England Maternity Review. We argued that improving investigations is crucial if safety in maternity is to be improved. In 2015 4,325 babies were stillborn or died in their first 7 days of life<sup>iii</sup> in England; the UK is reducing perinatal mortality three times

more slowly than some of our European neighbours<sup>iv</sup> such as the Netherlands, showing more can be done.

### **Sands RRR survey**

*To inform Sand's response to this consultation we ran a snap survey, advertised via Facebook, asking about some key aspects of the consultation. We are grateful to the 350 people who responded.*

## **Summary of Sands response**

There is no doubt that the current claims system does not serve families well and we welcome the objective to improve the experience of families who go through it. We very much welcome the objective to reduce harm by encouraging a learning culture.

We have a number of points to raise regarding the proposal as it currently stands.

### **1. Inclusion of babies who died**

We believe the RRR scheme should include term babies who died following severe avoidable harm in labour or soon after birth. In our survey 99% of respondents agreed on this. Comments included, *"Why would they not want to learn from avoidable deaths?"* and *"If the purpose is to learn and avoid such tragedies in the future it needs to include babies who die in childbirth"*

The potential to learn from these deaths must not be lost. In 2015 in the UK there were 119 deaths at term in labour and another 147 deaths of term babies in their first 7 days of life, totalling 266<sup>v</sup> (fewer in England only). A baby starting labour alive and dying is an event that should not happen. It is vital that failures in care contributing to each of these deaths are identified and incorporated in national learning if the government's ambition to reduce mortality by 50% by 2030 is to be achieved. It is hard to understand why deaths would not be included other than on financial grounds: the litigation pay-outs for baby deaths are far lower than for brain-injured children and the potential savings far less.

It is inexplicable to bereaved families that they would be treated differently from other families who have suffered the same harm, compounding a sense that the impact of a baby's death is taken less seriously. A two tier system is unacceptable. Bereaved families should also have access to a scheme which might make their claims experience less agonising.

### **2. Administration of the scheme**

We have serious concerns about the proposal that the NHS LA administer the RRR scheme. Families need to trust the system in order to accept the outcomes, but many perceive the NHS LA as being too closely associated with the Trusts delivering the care that has harmed their baby. Only 27% of respondents to our survey said the NHS LA should administer the RRR scheme. 52% said it definitely should not while another 21% didn't know. Respondents said,

*"I think it would be very difficult to be impartial when part of the NHS"*

*"It is important that the scheme is managed independently from the NHS"*

*"Surely there would be cases of conflict of interests and bias"*

Complete independence from the NHS and the Trusts is essential to secure families' trust both in practice and symbolically. 81% of respondents said a new separate independent body should be set up to administer the scheme, with only 10% against this option.

### **3. Investigation panels**

The independence of the panel is vital, as is the right mix of skills to carry out a robust investigation. We support the inclusion of specialist investigators, with specific skills in establishing what has

happened. Clinical experts on the panel must not be associated in any way, personal or professional, with the Trust being investigated. In reviewing their own care too many hospitals fail to admit mistakes, even to themselves. This must not be the case on RRR panels.

#### **4. Inclusion of parents in the investigation**

The proposal recognises that parents must have the opportunity to contribute their perspective of their care in the investigation process. Parents are the only ones present throughout the entire pathway of care. Their perspective, triangulated with the accounts of HCPs, can give valuable insights into the chain of events.

Recent reports have called for parental input into the investigation of their baby's death<sup>vi</sup>. A recent Sands survey and the PARENTS1 research study<sup>vii</sup> made clear that most parents want the opportunity to do so. Their contribution must be invited early on, be genuinely respected as an authoritative account, and be facilitated in a manner that is flexible around individual needs.

Parents also deserve to have a full, honest and timely account of the outcomes, with access to the complete evidence. It is crucial that information revealed in the investigation is not withheld from families, who would quickly lose trust in a system where they could not check evidence was consistent with their own experience of what happened.

Parents have the greatest interest of all in understanding what has happened to their baby and deserve to be heard.

#### **5. Support for parents**

In order to be able to participate fairly in a complex investigation families will need specialist support in order to make informed decisions about the choices on offer to them. Support must be more than simply legal advice, but should take account of families' inexperience, distress and vulnerability, encompassing their emotional and practical needs as well.

#### **6. Apologies**

We welcome recognition that when a baby has suffered severe harm, the family should receive an early apology. Many bereaved families tell Sands that an apology can bring some relief, though assurance that mistakes will not be repeated is as important. However an apology must be sincere to have any meaning. A standardised statement of regret issued as part of a tick box exercise would undermine any value.

When our survey participants were asked if they would be satisfied with an apology timetabled into the scheme, only a quarter said yes. Families are suspicious of advance timetabling of something so deeply personal. Respondents said,

*"That's too robotic and forced - no real feeling or meaning"*

*"It's meaningless without them understanding what is lost and honouring the devastation"*

*"It's peoples' lives, not a courtroom"*

When a baby is harmed families suffer devastating, enduring pain. This must be acknowledged in a human and genuine way, not just for the family's sake, but also to grasp the profound seriousness of the impact and as a motivator for minimising future harm.

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<sup>i</sup> MBRRACE-UK Perinatal Confidential Enquiry Term, singleton, normally-formed antepartum stillbirth. Leicester 2015

<sup>ii</sup> MBRRACE-UK Perinatal Confidential Enquiry Term, singleton, normally-formed antepartum stillbirth. Leicester 2015

<sup>iii</sup> <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/childhoodinfantandperinatalmortalityinenglandandwales/2015>

<sup>iv</sup> V Flenady et al, Stillbirths: recall to action in high-income countries. Lancet 2016;

<sup>v</sup> Each Baby Counts: key messages from 2015. RCOG 2016

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- <sup>vi</sup> MBRRACE-UK Perinatal Confidential Enquiry Term, singleton, normally-formed antepartum stillbirth. Leicester 2015; Each Baby Counts: key messages from 2015. RCOG 2016; Kirkup Report of the Morecambe Bay Investigation, 2015
- <sup>vii</sup> Parents' Active Role & Engagement in Their Stillbirth/Perinatal death review (PARENTS1) study, University of Bristol and North Bristol NHS Trust