Responses from La Leche League GB to the NICE consultation on Sudden Infant Death Syndrome

La Leche League GB would like to offer input into the *National Institute for Health and Care* consultation on *Sudden Infant Death Syndrome* (SIDS).

1. The NICE Addendum states "*Due to the various methodological and study design issues of the included studies in this update mentioned above, the evidence base could only illustrate associations and a cause-effect relationship could not be inferred*"

- LLLGB says: Research studies on the subject of bed-sharing often use different and confusing definitions. The 2013 article by Carpenter et al, *Bed-Sharing when parents do not smoke: is there a risk of SIDS?*, combined five different studies with varying definitions, including what was meant by bed-sharing.

- In the studies on SIDS there was no consistency in the data collected so there are missing variables which can make a significant difference to the results. One question which was sometimes omitted was how the baby was fed, and this makes a big difference when talking about breastfeeding and bed-sharing as opposed to formula feeding and bed-sharing.

- In some research the definitions of co-sleeping have been unclear. For instance "solitary sleep" might mean a baby alone in another room, or in the same room but not the same bed. "Co-sleeping" might mean a baby in the same room as another person, or a baby in a bed with someone, or a baby asleep with someone on a sofa or other risky shared sleep surface. "Bed-sharing" might be with the baby's mother, or with someone else, or more than one person, or sharing a sofa or recliner with his mother. The person could be awake, asleep, drunk, sober, an adult not the mother, or even another child.

- For example in 2010 there was a campaign in Milwaukee County against bed-sharing. When the statistics were investigated it was found that all the "bed-sharing" deaths in the past year had involved adult alcohol use, a baby on a pillow, difficult living conditions and/or smoking. Every death involved a formula fed baby.

- A 2009 study by public health officials in Alaska which aimed to tease apart known risk factors and look at them separately found that 99% of the babies who died had at least one of these risks: Face down position, sleeping with someone other than the mother, maternal tobacco use, impaired bed partner, sofa or waterbed. It was not the bed-sharing but the condition of the adult and safety of the surface[1].

- Gathering information at a death scene is complicated and research conclusions are only as good as the data collected. In some places a doctor with specialised training investigates an infant death; some places don't require any special training. Some places have a death scene report form, but it isn't used everywhere and bed-sharing is not always clearly defined.

- An often-cited 2005 study did not collect data on alcohol consumption as previous experience had demonstrated the difficulty of obtaining accurate information[2] thus ignoring a key variable for both SIDS and suffocation. Some examiners record how the baby was fed, others don't. Some ask abut smoking, and some don't. Sometimes information given by the adults involved isn't accurate.

- This huge range of approaches, definitions, levels of accuracy, detail and training, provide the data for the "never bed-share" studies. When committees and support organisations include parents who have lost a baby to SIDS it is understandable that strong emotions will be involved.

- Breastfeeding mothers and babies sharing sleep is a biologically normal behaviour, while formula feeding and separate sleep are departures from the norm. It is these behaviours that need to be shown to be effective and safe, not the other way round. In some reports on SIDS and other sleep related deaths, breastfeeding mothers who do not smoke and have not consumed alcohol or arousal-altering medications, are considered a sub-group to be discounted from the analysis – whereas they should be the normal, starting point. A first step in looking at infant deaths in adult beds would be to look at what was wrong with the beds, not what was wrong with the mothers.

2. The NICE addendum states that their definition of co-sleeping includes sharing a bed or any other sleep surface such as a sofa or chair.

- LLLGB says that sofas and chairs represent a much greater risk that safe bed sharing and that to issue a blanket recommendation based on such variable circumstances is misleading. Babies have a biological need to feed during the night, and mothers are hardwired to respond. Breastfeeding releases hormones which aid rest and relaxation in the nursing dyad and make both sleepy. If warnings about bed-sharing means mothers stop taking their babies into bed with them they still need to feed their babies somewhere. This will probably be in a chair or on a sofa, which are riskier places to fall asleep with a baby than in a bed when appropriate measures have been taken.

3. The NICE Addendum states "*it would be inappropriate to use the term risk when considering SIDS and co-seeping as the causes of SIDS are likely to be multi-factional and a* ***possible*** *causality link with co-sleeping is not clearly defined".* It went on to say "*It cannot be definitely stated that co-sleeping is a risk for SIDS. Some of the reviewed evidence showed that there is a statistical relationship between co-sleeping and SIDS. This means that, where co-sleeping occurs there may be an increase in the number of cases of SIDS. However, the evidence does not allow us to say that co-sleeping causes SIDS."*

- LLLGB says that no one has proposed a physiological mechanism what would cause a baby to die of SIDS just because he is next to his non-smoking mother - and since mothers and babies are hardwired to be together it wouldn't make any sense.

- LLLGB would like to draw attention to the differentiation between SIDS and Accidental Suffocation and Strangulation in Bed (ASSB). The four biggest risk factors

associated with SIDS are smoking[3], laying a baby tummy down for sleep[4], leaving a baby unattended[5] and formula feeding[6]. It happens in a small group of vulnerable babies who have very specific but undiagnosed health issues. Babies may become distressed if their need to be close to their mothers at night is denied and a vulnerable baby may also be more sensitive to stress. SIDS is different to the risk of Accidental Suffocation and Strangulation in Bed (ASSB) which happens when a baby is in an unsafe sleep environment with an impaired carer.

- The lowest SIDS rates in the world are in countries where bed-sharing is traditional, for instance parts of Asia and South Asia[7]. It doesn't seem to be a matter of geography as when people from a low-risk cultures move to other countries if they bring their traditions with them they also tend to bring along a low rate of SIDS[8]. The US has a higher rate of SIDS than just about anywhere else and the four big risk factors for this are mentioned above. Bed-sharing is not one of them.

- Putting two different risks together is misleading and does not allow parents to make informed decisions. While SIDS is something which affects a small group of vulnerable babies, parents need to be aware of ASSB (breathing hazard) risks. Making sure a bed is as safe as possible, free of suffocation and injury risks, having a smoke free home, not using arousal- altering medications or alcohol, and breastfeeding are all ways to ensure a healthy baby and his family get a good night's sleep. Even if a mother does not intend to bed-share, ensuring her sleeping area is safe will help on those nights when she finds herself nursing in bed and falling asleep.

- Four researchers who have used very clear definitions in their studies are Drs. Helen Ball (UK), Nils Bergman (South Africa), Kathleen Kendall-Tackett and James McKenna (USA). Their conclusions support the safety and normalcy of bed sharing.

- Dr McKenna says that the amount of CO^2 the mother expires in her breath acts to stimulate infant breathing. Expelled CO^2 appears to act as a potential back-up should the baby's own internal drive to breathe falter or slow, since the baby's nasal regions can both detect and respond to the presence of this gas by breathing faster.

- He also says that babies who sleep with their mothers and breastfeed spend less time in the deepest stages of sleep (three and four), from which arousal is more difficult should the baby need to awaken quickly to terminate a dangerous apnoea. Instead, co-sleeping babies spend more time in lighter stages of sleep (one and two) which is thought to be physiologically more appropriate for young infants, and more natural and conducive to safe sleep for babies. The shorter durations of deeper stage sleep promoted by co-sleeping can potentially protect those infants born with arousal deficiencies (suspected to be involved in SIDS).

4.

- LLLGB believes that suggestions have to be "doable". Losing a baby is such an incredible tragedy that it is understandable to look for ways to prevent this. However most breastfeeding mothers sleep with their babies at least some of the time and it

is unrealistic to try to stop this. Creating one rule for a specific high-risk situation and applying it to everyone will not work. Tired mothers have to feed their babies somewhere and making everyone feel they are at risk can cause damage in other ways. Mothers may turn to formula or cereal in the hope of getting their baby to sleep longer; they may fall asleep in unsafe places or undertake a sleep-training programme which has associated risks.

- LLLGB believes it would be better to offer information to parents to make shared sleep as safe as possible. Whilst no sleeping environment can be entirely risk free, studies at Durham Parent-Infant Sleep Lab have found that mothers who sleep with their breastfed babies in bed adopt a protective position that makes overlaying difficult, and smothering by bedding unlikely. It has been observed that babies "demonstrably do not overheat" and that they breastfeed more successfully and for longer, which has significant health benefits for mother and child.

- Safe Sleep campaigns which tell mothers their baby should not sleep in their bed, a couch or a chair, give that mother no information about where she can feed her baby at night when she is likely to fall asleep. Mothers need to have a clear explanation of SIDS and ASSB risks, with different recommendations based on their different lives. They need full information about their options, not alarmist threat messages.

- Policies designed to protect the health of a few babies should not be applied to all if harm can result. The blanket recommendation of this analysis that parents "simply avoid bed-sharing" may well scare women into making decisions which are not right for them, their family or their baby, and could lead to babies being breastfed in places where it would be riskier for women to fall asleep. Ultimately it could also lead to women stopping breastfeeding because they are too worried about where to feed.

- If this recommendation closes down the opportunity for discussions about safe bed-sharing it denies parents whose babies are at low risk for SIDS (healthy term births, breastfed, non-smoking, non alcohol-consuming parents) the opportunity to make an informed decision and may lead to parents feeling they need to lie about their choices

- It is vitally important that parents are aware of the need for safe sleeping arrangements and of circumstances which might cause risk. They need to know abut the risks and benefits of co-sleeping and unsafe co-sleeping practices so they can make their own informed decisions. Trying to instigate a ban is not a reasonable or effective response to such an instinctive and natural human behavior.

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