

Annex A – Covering Template for Responses

Please complete the attached cover sheet when sending evidence, indicating the set of questions to which a response is being provided and contact details of the person for any follow-up queries.

Contact details for respondent	
Name	
Job title	Campaigns and Policy Manager
Do you represent an organisation? (if so, name of organisation and type: e.g. voluntary, public body, private company).	BLISS, the premature baby charity (voluntary)
Postal address	2 nd and 3 rd Floors, 9 Holyrood Street, London Bridge, London SE1 2EL
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	Which area of the review are you responding to? (please mark X)
Prevention strand	X
Review of disabled children	
Strategy for youth services	
Review of high cost, high harm families	X



BLISS response to Comprehensive Spending Review 2007: Call for evidence: DfES/HM Treasury Joint Policy Review on Children and Young People

Introduction

BLISS, the premature baby charity, is dedicated to making sure that more babies born prematurely or sick in the UK survive and that each one has the best quality of life. BLISS aims to realise this by:

- promoting new developments and innovations in care
- supporting parents and families
- campaigning for improvements in neonatal care.

We welcome the opportunity to respond to this consultation and we will make a number of points on improving life chances and addressing risk factors for premature birth.

We have been the leading charity working for sick and premature babies for over twenty five years. A major part of our work is the provision of support to parents and carers such as a telephone helpline, publications on specific issues when caring for sick and premature babies, online information and a website message board.

In addition to our board of trustees, our work is informed and monitored by a Nursing Advisory Panel, a Medical Advisory Panel and a Parent Advisory Panel.

We have chosen to respond only to questions which we feel are relevant to the users of our services.

B1 (Preventative strand)

How can targeted and specialist services intervene earlier to address problems before they become acute?

BLISS believes that targeted interventions can be made at the earliest possible point – at birth and in some cases, earlier. We believe more should be done, and earlier, to target vulnerable groups, particularly those at risk of giving birth to premature and low weight babies.

BLISS would like to address two key points:

- early intervention for vulnerable groups who are more likely to become parents to premature and low birthweight babies, and who have high rates of infant mortality (further details of who these groups are is in our response to B4)
- more effective intervention when babies are born prematurely

The first step towards addressing these issues is identifying those groups that are vulnerable, and acknowledging the growing need for neonatal care. Our response to B4 outlines some of the groups that we have found to be particularly at risk. BLISS has found that these vulnerable groups vary both in geographical location, socio-economic grouping, and ethnic background.

BLISS would like to see more information provided for all parents-to-be about prematurity when they attend neonatal clinics or classes, so the shock of having a child born early is reduced and they are better equipped emotionally and practically to cope. However, as we have said, there are also identifiable groups that are particularly prone to low birthweight and premature babies. BLISS recommends that alongside existing support provided for these groups, such as teenage and single mothers, ethnic minorities and those from socially deprived backgrounds, more is done to educate them about the chances of their having a premature baby. Should their baby be born prematurely, more emotional and practical support is needed post-natally to help parents from at-risk groups cope with their premature baby. Furthermore, where it is appropriate, more needs to be done with some groups highlighting and educating them about the risk factors associated with certain types of behaviour on the chances of their baby being born prematurely and/or at low birthweight.

Addressing these health inequalities and risk factors will not only help improve life chances for those babies that are born premature, it should also have an effect on infant mortality rates in the UK. While this rate nationally has slowly been going down, if infant mortality in the UK is broken down by geographical area, then babies in some parts of the UK are eight times more likely to die before their first birthday compared to other areas. Furthermore, there are strong causal links between social deprivation and the higher prevalence of low birth weight babies. The effective targeting of these vulnerable groups with education, dedicated support and earlier intervention will go some way to achieving the government's stated aim of

*"starting with children under one year, by 2010 to reduce the gap in mortality by at least 10% between 'routine and manual' groups and the population as a whole"*¹

While there are risk factors that can be reduced by public health campaigns and awareness-raising exercises, often a baby is born prematurely for no single identifiable reason. We are always going to have a significant minority of babies that are born prematurely. Therefore, the problem of provision for premature and sick babies needs to be addressed directly.

BLISS research has shown that neonatal services in the UK are understaffed and overstretched. The short-term health and longer-term life chances of babies that are already placed at a disadvantage is being jeopardised. Research by the National Perinatal Epidemiology Unit, commissioned by BLISS, found that in a period of six months, almost 90 per cent of neonatal intensive care units had had to turn away seriously ill babies because of a lack of staffed cots.² Furthermore, only three per cent of neonatal units met the standard of one to one nursing recommended by both BAPM and a Department of Health Working Group.³ The circumstances that place babies in these situations are unfortunate, but not irredeemable. BLISS recommends that increased funding is allocated to increase nursing levels in intensive neonatal care, in line with standards for adults and children, to one nurse to one patient.

¹ 2004 Spending Review PSAs, Chapter Three Department of Health, HM Treasury July 2004

² Weigh less, worth less? BLISS July 2006 www.bliss.org.uk

³ ibid

What would be the impact of more preventative services and early intervention on the life chances of children and young people and on the value for money of public spending on children, young people and families?

It is important to remember that babies are part of children's health services and their needs are just as important as the needs of children and young people. BLISS believes that babies are individual human beings, with all the rights and entitlements that humans of all ages enjoy. Whilst this may seem to be a statement of the obvious, our research and the experience of parents and babies shows that in important areas, babies are not given the same consideration as children or adults. For example, only 20 per cent of neonatal units in the UK regularly use a pain tool to assess pain in sick and premature babies.⁴ Another example is that while adults routinely receive one to one nursing in intensive care, only three per cent of units in the UK can offer this level of care.⁵

Better neonatal care would improve the life chances of a significant minority of babies that require special care when they are born. One in eight babies, which equates to 80,000 babies in the UK every year, will need to spend time in hospital before they go home. These babies are already born at a disadvantage, and giving them inadequate care further jeopardises their future welfare. BLISS, along with British Association of Perinatal Medicine (BAPM) and a Department of Health (DH) working group recommends that babies in intensive care receive the same standard of nursing care as adults and children; that is, one nurse to one patient. In most units, the best that parents can expect is one nurse to two or three babies.

Better care, and greater intervention upstream would also help address disparities in infant mortality across the country, as mentioned early.

This increased level of neonatal nursing would offer cost savings elsewhere in neonatal services. BLISS research revealed that the reason behind many transfers between neonatal units was due to a lack of staffed cots. While BLISS obviously appreciates the need for transfers for medical reasons, transfers that occur for non-clinical reasons because of a lack of staffing are unnecessary. Besides exacerbating a difficult and traumatic experience for parents, these transfers can also prove expensive and time-consuming for units. Increased staff levels would not only improve patient care, but also save time and money.

Furthermore, neonatal care has historically been underfunded compared to equivalent adult intensive care, so increased spending on care for sick and premature babies would represent value for money in terms of addressing past inequalities. A written parliamentary answer by Rosie Winterton MP, Minister of State for Health on 15 June 2005 to a question from Edward Leigh MP revealed that the national average per day funding for adult intensive care is £1,328, while the same figure for neonatal intensive care is £838. BLISS recommends that increased spending in neonatal care be targeted at both preventative measures and increased nursing. It is our belief that this represents value for money, and addresses current clinical needs.

⁴ Special care for sick babies – choice or chance? BLISS July 2005 www.bliss.org.uk

⁵ Weigh less, worth less? BLISS July 2006 www.bliss.org.uk

For more information on neonatal networks and nursing levels, please see the BLISS report *Weigh less, worth less?* which is available at www.bliss.org.uk.

B4 (Terms of reference for High Cost, High Harm families)

Who are these families? How can we define them and how many of them are there?

A very important indicator for children's health and, more widely, public health is infant mortality. Infant mortality and low birthweight figures can help us identify particularly at risk groups. For example, if infant mortality in the UK is broken down by geographical area, then babies in some parts of the UK are eight times more likely to die before their first birthday compared to other areas. Similarly, there are strong causal links between social deprivation and a higher prevalence of low birthweight babies. Low birthweight is a strong predictor for infant mortality, and of health outcomes in childhood and adulthood.⁶

BLISS has identified a number of social groups that have particularly high rates of low birthweight, and therefore represent particularly high risk groups.

- **Teenage mothers.** This country has the highest rate of teenage pregnancies in Europe and again these pregnancies are at high risk of resulting in a premature or low birth weight baby.⁷
- **Single mothers.** There are strong links between being a single mother at the time of birth and birthweight. Sole registered births registered by mother alone are much more likely to be of low birthweight.⁸
- **Ethnic minorities.** Mothers from non-white ethnic backgrounds have a 62 per cent increased risk of giving birth to a low birthweight child, after taking account of their age at the time of the birth, household and area characteristics.⁹
- **Immigrants.** Mothers who were born in Pakistan have the highest risk of a low birth weight baby¹⁰.
- **Substance and alcohol abusers, cigarette smokers.** These problems are particularly prevalent in socially deprived backgrounds.

Clearly there are certain demographic groups that are particularly at risk of having low birthweight babies, and are, by extension, vulnerable to infant mortality. In addition to these socio-economic groups, BLISS has identified areas of the country that have particularly high rates of infant mortality. In March 2006 we undertook a study into these regional variations. An answer to a parliamentary question revealed infant mortality rate by Primary Care Trusts (PCTs). Taking a three year average (2002-2004) and making an adjustment in order to account for the areas of very low

⁶ *Weighing the evidence: How is birthweight determined?*, Spencer N, Radcliffe Medical Press 2003

⁷ *Risk factors for low birthweight based on birth registration and census information, England and Wales, 1981-2000*, National Statistics 2006

⁸ *ibid*

⁹ *ibid*

¹⁰ *ibid*

birth rate, we published a league table showing the 'worst' and 'best' areas for infant mortality in England.

Worst area for infant mortality	
AREA	RATE
1. Central Birmingham	12.4
2. North Kirklees	11.2
3. Central Bradford	10.4
4. East Birmingham	9.2
5. Central Manchester	8.6
6. South East Sheffield	8.4
7. Nottingham City	8.3
8. Coventry	8.2
9. Southwark	8.1
10. Newham	7.9

Best area for infant mortality	
AREA	RATE
1. East Elmbridge and Mid Surrey	1.5
2. East Devon	1.8
3. Central Suffolk	1.9
4. South Somerset	2.2
5. Chiltern and South Bucks	2.2
6. Hertsmere	2.4
7. Mid-Hampshire	2.4
8. Melton, Rutland and Harborough	2.6
9. Scarborough, Whitby and Ryedale	2.6
10. Maldon and South Chelmsford	2.7

Some of these variations are shocking. Central Birmingham (Heart of Birmingham PCT) has eight times the number of babies dying than the lowest rate in the country which is in Mid-Surrey. Generally, the figures show worse outcomes for babies born in large cities in the North West and Midlands compared to the better areas concentrated in the suburban South.

Reducing these inequalities in outcomes for babies should be a national priority. This should be done by introducing national infant mortality targets and providing extra funds to enable real progress in reaching these targets. Equally the issue must be tackled on a local level with targeted interventions for the high-risk groups identified above. Primary care trusts should play a leading role in reducing infant mortality in their area.

For more information on infant mortality and addressing health inequalities, please see the BLISS report *Weigh less, worth less?* which is available at www.bliss.org.uk

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