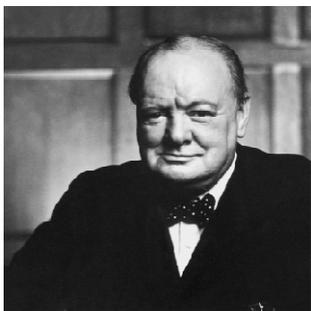
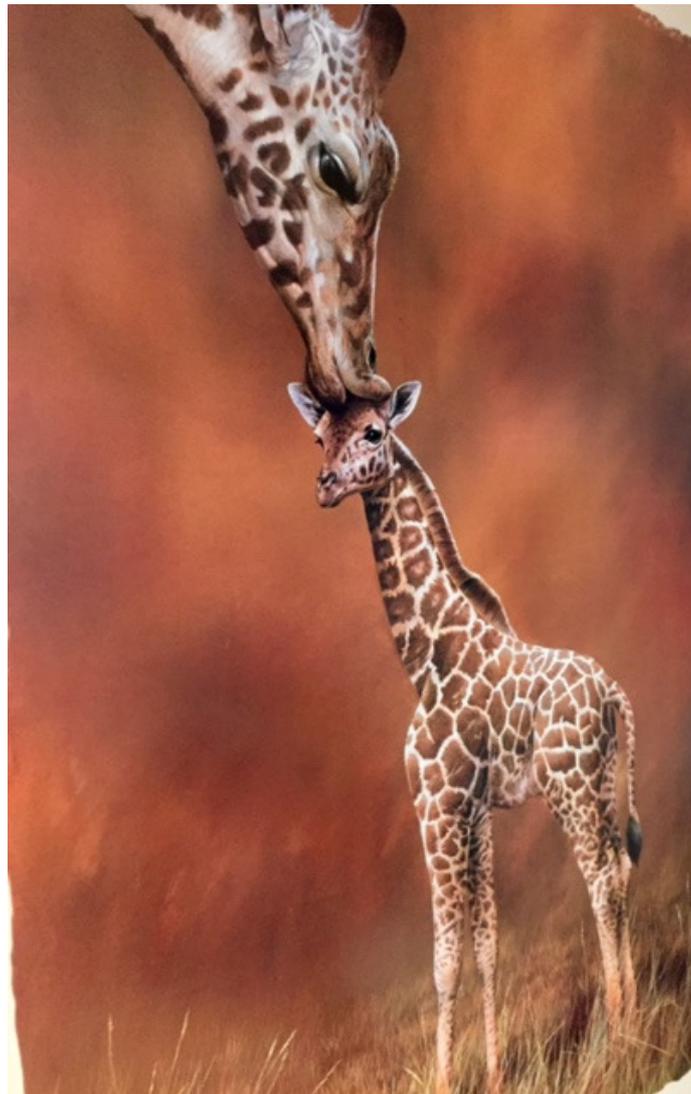


# Abusive Head Trauma: The Case For Prevention



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**Winston Churchill Memorial Trust Travel Fellowship  
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## **DEDICATION**

**Michael and Rosie – my inspiration!**

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## Executive Summary

**Aims:**The aim of this Fellowship was to explore international programmes related to the prevention of child maltreatment with a particular focus on the devastating form of child abuse that is Abusive Head Trauma (AHT) in infants and to gain an understanding about the wider context of the delivery of care and the systems and processes in which they are provided and commissioned. Specific outputs from the Travel Fellowship include the development of a UK based primary prevention programme.

The Fellowship has included the observation and study of the powerful programmes visited and the passionate and dedicated professionals who lead and research them. A critical analysis of the applicability of the different programmes within the UK health and social care context is considered alongside the evidence base underpinning prevention of Abusive Head Trauma and helping parents and caregivers cope with crying.

**Findings:** The findings highlight what makes AHT prevention programmes and child protection, family support services generally, successful. The constant forward planning for funding and rooting the programme within a secure organisational infrastructure cannot be underestimated.

The development of a multi agency co-ordinated programme that can fit into mainstream service delivery, that has a simple message, is well led and operates throughout the public health levels of prevention spectrum are key success indicators.

Careful thought should be given to measuring success of a programme from the outset including the resources involved in data collection and analysis and the need to respond to current political imperatives in order to attract funders.

A hospital based programme would reach more men. The programme would extend into the community embedding its message by repeated reiteration of the essential messages throughout the first two months of a baby's life at the least and supported by accessible materials. A one size fits all programme is unlikely to work and flexibility to support local delivery whilst maintaining fidelity to the essential core message is crucial.

### **Recommendations:**

- Gain endorsement and support from key stakeholders to design and implement a coordinated AHT prevention programme focusing on helping parents/caregivers cope with crying.
- Identify champions from each agency and within stakeholder organisations.
- Establish a multi agency steering group including parents/carers and families affected by AHT to co-design the detail of the campaign.
- Consider purchase or development of bespoke materials.
- Work with interested Universities to develop research protocol/evaluation design and bid for grant funding.
- Pilot, evaluate and roll out agreed programme.
- Disseminate through publication and conference presentations.

## 1. Introduction

Abusive Head Trauma (AHT), also known as Shaken Baby Syndrome, is a devastating form of child abuse. Catastrophic injuries which result often present in a constellation including intracranial injuries, retinal haemorrhage and certain long bone fractures and spinal fractures. The causal mechanism in cases of AHT is rarely confirmed and may well include elements of both impact and acceleration/deceleration injury. 1 in 14 cases is fatal before hospital discharge and half of severely injured survivors will die before 21 years of age.

Despite the persistent incidence of AHT in the UK (20 – 24 per 100,000) there has never been a fully co-ordinated multi agency programme aimed at the prevention of AHT. Pockets of areas have designed materials and the National Society for the Prevention of Cruelty to Children (NSPCC) have produced some extremely thorough programmes the latest of which was launched late in 2016. However, the degree to which different professionals use the materials, promote a consistent message and show the effectiveness of their intervention over a sustained period of time is not reflected in the literature and certainly has not had any impact on the incidence of AHT in the UK.

The aim of this Fellowship was to explore international programmes related to the prevention of child maltreatment with a particular focus on AHT in infants and to gain an understanding about the wider context of the delivery of care and the systems and processes in which they are provided and commissioned.

Specific intended outputs included:

- Establishment of a multiagency/multi disciplinary working party the terms of reference of which will include enhancing assessment and intervention of parenting capacity and coping ability in relation to excessive crying in infancy within health, education and social care delivery. The group will include parents.
- Development of a suite of prevention programmes aligned with public health levels of prevention.
- Pilot programmes within selected acute and community health environments.
- Complete impact evaluation of pilot including feedback from parents and professionals.
- Finalise programme and present to Clinical Commissioning Groups and Local Safeguarding Children Boards.
- Secure resource for integration of programmes into mainstream services.
- Apply for research grant capture bids for research study.
- Disseminate findings.

My interest in this area of work stems from my first exposure to the devastation caused to children and families during the late 1990s in my role as Senior Nurse: Child Protection in Leeds Teaching Hospitals NHS Trust. As a registered Health Visitor I have always been focused on preventing child abuse from happening in the first instance at a primary level of intervention and I began to research why people shook their babies and what could be done to prevent it, whilst accepting it was not possible to prevent all cases of abuse.

The programmes I had chosen to visit as part of my Travel Fellowship included programmes about which I had studied for many years. It was important for me to understand how they were delivered in the places from which they were created and to understand the challenges and opportunities in programme delivery as well as the ways in which the programmes had been developed over the years. Gaining an understanding of the healthcare context was also extremely important in order to gauge how applicable the programmes visited would be to the UK culture and health and social care context.

Programmes visited included (Appendix One):

- SEEK (Safe Environment for Every Kid) Baltimore, Maryland
- Shaken Baby Syndrome Prevention Programme Hershey, PA
- Safe Babies New York Buffalo, NY
- Period of Purple Crying Vancouver, BC
- Period of Purple Crying Helena, MT
- Period of Purple Crying Wichita, KS

In addition to these specific programmes and in order to gain a wider sense of context, I visited three Child Advocacy/Resource Centres:

- Lewis and Clark County Child Advocacy Centre Montana
- Pinnacle Health Children's Resource Centre Pennsylvania
- Kansas Children's Services League Kansas

My Travel Fellowship also included a 3 day international conference held in Montreal hosted by the National Centre of Shaken Baby Syndrome (Appendix Five) . The conference included representations of programmes, research from professionals and families and was a rich source of inspiration and information as well as providing some confirmation of my emerging findings.

These centres provided services that ranged from primary preventative programmes including the AHT prevention programmes to child abuse medical and evidence facilities. A comparison in the UK would be like providing video suites in police facilities within fully functioning Children's Centres. There is potential to invest in UK children's centres to provide the same 'wrap around' and non-stigmatising approach. However, children's centres in the UK are under significant threat with many being closed as local authorities and the NHS face unprecedented financial pressures. All of the centres I visited spoke about the importance of planning to source funding as part of a 3 year planning cycle underlying the challenges of funding prevention.

This report describes the case for prevention of AHT by providing a review of the literature on the topic. The 'findings' section of the report will provide insight into what the different organisations visited offered in terms of the wider child abuse prevention and family support programmes and will focus specifically on the AHT prevention programmes. The report will consider the funding and infrastructure of the programmes as well as the challenges and opportunities to successful implementation. Finally the report will describe how the findings of the Travel Fellowship can and are being related to the UK and will conclude by describing how the aims of the Fellowship have been achieved with a short series of recommendations for the proposed programme implementation and dissemination.

## **2. Literature Review**

### **2.1 Incidence**

Abusive head trauma (AHT) affects one in 4000–5000 infants every year and is one of the most serious forms of physical child abuse that has a high associated mortality and morbidity (Kemp 2011). Kesler et al (2008) showed incidence of 26 per 100,000 during the first year. Barlow and Minns in 2000 demonstrated the incidence of AHT as 24.6 per 100,000 of babies in the first year of life. Kemp (2011) describes three UK studies that give a similar incidence of between 20 -24/100,000 rising to 36/100,000 in babies under 6 months. In practice, an average sized District General Hospital can expect to see a case every 1 or 2 years. At Pennine Acute Hospitals NHS Trust, there have been 5 cases in 2 years. 2.6% of American parents in 2008 admitted to having shaken a child under the age of 2 years and 9% felt like shaking their infant. It is, therefore, possible that cases which come to the attention of clinicians are only a proportion of cases of AHT.

### **2.2 Demographics**

Kesler et al (2008) found that males represent 70% of perpetrators. Their study also provides strong evidence that, although AHT can occur in every socio-economic groups, there are significant demographic differences between the general population and those families in which AHT occurs. Compared with the population of Pennsylvania, both mothers and fathers were more likely to be younger, less educated and unmarried. Both mothers and fathers were often Africa American and fathers more often Hispanic. Mothers more often smoked in pregnancy, sought ante-natal care late and how birth weight babies. However, caution should be given to interpreting the statistics as these families are more likely to be reported for AHT (or conversely, that families conforming to other demographics are less likely to be reported). A previous study (Jenny et al 1999) found that 'missed' cases of AHT more frequently involved 'intact' and 'Caucasian' families.

Altman et al (2010) also concluded that Fathers and male surrogates are nearly 5 times as likely as mothers to shake an infant. From the parents survey only 40.4% of fathers watched the educational video that was part of the prevention package evaluated. Finding better ways to reach male caretakers should be a priority.

### **2.3 AHT as a Public Health Issue.**

AHT, as with all child abuse, is a public health issue. The prevention messages relating to AHT are clearly aligned with the public health levels of prevention which are primary (preventing a problem before it starts), secondary (intervening at the early stages of an emerging problem) and tertiary (intervening when harm has occurred to prevent further harm and limit damage). A further level which could be described as 'Supportive' would help support those families affected by AHT and foster a culture where education comes from within communities.

Berger et al (2011) show a significant increase in the rate of AHT in a 74 county region during a recession compared with the 4 year period before it. Although it isn't possible to prove a causal relationship between AHT rate and the economy, the data are compelling enough to influence policy and clinical decisions. Specifically, the

presence of an association between the economy and the AHT rate should be sufficient to spur a discussion of specific stressors and mediators of these stressors and how they could be modified to decrease the risk of AHT to young children. From a clinical perspective, this association might warrant changes in the threshold for physicians to evaluate for AHT during times of economic stress.

The relationship between recession and AHT rate might not be surprising given previous data that supported an association between poverty and all types of physical abuse. However, this is the first study to focus on a specific exposure, the recession, and a specific outcome measure – county level AHT rates.

Individual poverty wasn't assessed per se but recession as a societal level risk factor was. Although work in public health is often limited to identifying individual level risk factors to identify people at high risk, the greatest improvements in populations health are likely to derive from societal interventions, because the majority of cases of poor public health outcomes arise outside the more easily identified extremes of risk. Therefore, although targeting people at high risk can have a dramatic effect on individual risk, because only a small percentage of people are at high risk, this approach might not have a major effect on population –level rates.

## **2.4 Parenting Support**

The notion that parents do not necessarily have an innate ability to parent effectively is now recognised and the need for “efficacy in parent education” has grown (Miller and Sambell 2003:33). Moran et al (2004) suggest the likely benefit in ‘normalising parenting support as a universal right’ as most parents need support at some point’. With a particular focus on parental discipline, Redman and Taylor (2006) point to the need for health professionals to provide consistent advice about alternatives to physical punishment to parents who are seeking those alternatives. This view is supported by Iwaniec (2006) who emphasises that parents who are faced with parenting difficulties should be provided with help when it is requested. The dangers of inappropriate intervention are described by Dakof and Taylor (1990) who stress that individuals who request help and don't receive it, or who receive criticism of how they are handling the situation are discouraged from seeking further help.

The problems that parents of a persistently crying baby might bring to professionals is specifically discussed by a variety of authors. Long and Johnson (2001) highlight the evidence that those parents and carers who complain to professionals that their baby cries excessively, actually do have a baby who cries more frequently and for longer than most (St. James-Roberts et al 1993; Baildam et al 1995). Bar et al (2000) confirm that babies who cry excessively will do so despite the quality and level of parenting provided and all babies have a normal crying curve which starts at 2 – 3 weeks and peaks at 5 – 6 weeks. Long and Johnson (2001) found that a baby's excessive crying can promote feelings of ‘living on the edge’, social isolation and ‘gradual introversion’ for families. They highlight the fear parents have of losing control:

“The most significant fear for parents... was the danger of non-accidental injury to the baby. Such fears, exhaustion, and the occurrence of intermittent period of especially heightened tension, led to a pattern of approaching and withdrawing from a point of total loss of control: living on the edge”. (p158).

If professionals are to understand the value of their interventions aimed at helping parents cope with the stress incurred by their child's behaviours such as persistent crying, there is a need to understand the context in which that stress manifests itself, how and why it may increase, the potential outcomes that may result and what helps increase parental coping strategies.

### **2.5 Parenting behaviour and stress:**

Stress is seen as an especially prominent antecedent in violence towards children. Stressors include background or environmental stressors such as noisy environments and in particular, uncontrollable noise (Straus 1980; Geen 1990). A crying baby can be described as uncontrollable and its effects on parents and caregivers can be powerful (Long & Johnson 2001; Wade et al 2005). Smith et al (1995) found that a combination of factors were prevalent in families where there were high levels of physical punishments. Underpinning these discussions is the proposal for a model of parenting which is based on Bronfenbrenner's (1979) ecological perspective of parenting which considers parent-child interaction and behaviour amid the context of parental characteristics, child characteristics and family environment (Belsky 1984). These factors are explicit within the DH (2005) 'Framework for the Assessment of Children in Need and Their Families' and are as relevant today in the application of Early Help Assessments as they were then.

Watkins and Cousins (2005) draw attention to the interplay between situational context and structural context in which physical punishment of children occurs. Whether or not parents cross the line between legitimate and non-legitimate punishment seems to stem, in many cases, from a battle to cope beneath a constellation of stressors leading to frustration and anger.

The effect infant crying and other behaviours, such as poor sleeping patterns and difficulties in feeding, have on parents, includes reduction in coping ability, poor parent-child interaction, reduction in self-esteem, exhaustion, frustration and anger (DH 1995; Iwaniec 2006; Long and Johnson 2001). All of these behaviours can potentially be the trigger which, in some people, will manifest itself as frustration, then aggression (Berkowitz 1978). In addition inconsolable crying can trigger a series of events that may lead some parents to shake their baby with sometimes fatal consequences (Showers 1992; Reijneveld et al 2004; Barr et al 2006).

The success of any coping strategy depends on the controllability of the situation. Coping strategies relying on problem solving may lead to increased frustration and distress when used in a context where the stressor cannot be controlled and where there is no response (Folkman 1992; Compas et al 1988). Taking excessive infant crying as an example, Long and Johnson (2001) found parents eventually accepted that coping involved support *through* the problem rather than *solving* the problem (i.e. stopping the baby crying) which was frequently an impossible task. The need for a careful approach towards a responsive professional intervention that is rooted in evidence is, therefore, crucial.

In conclusion, the literature on the subject of parental coping draws attention to the need for parenting education and support which is 'normal' and the professional

response to which should be 'universal'. The stress of a crying baby, which every parent will experience as the increase in infant crying is normal, can impact on parenting ability and can have a potentially negative impact on child welfare.

## **2.6 Cost**

The cost of AHT, whether or not the baby survives, are significant potentially including initial inpatient hospitalisation (PICU), long term medical services including physio therapy, occupational therapy, speech and language therapy, special education needs input, foster care, family proceedings, criminal proceedings, prison costs, probation costs, Serious Case Review costs, loss of societal productivity and occupational revenue.

Peterson et al (2014) assessed 1209 patients with AHT and 5895 matched controls. Approximately 48% of patients with AHT received inpatient care within 2 days of initial diagnosis, and 25% were treated in emergency departments. AHT diagnosis was associated with significantly greater medical service use and higher inpatient, outpatient, drug, and total costs for multiple years after the diagnosis. The estimated total medical cost attributable to AHT in the 4 years after diagnosis was \$47 952 per patient with AHT (2012 US dollars) and differed for commercially insured (\$38 231) and Medicaid (\$56 691) patients. They concluded that children continue to have substantial excess medical costs for years after AHT. These estimates exclude related nonmedical costs such as special education and disability that also are attributable to AHT.

### 3. Findings – the programmes

**3.1 Safe Environment for Every Kid (SEEK)** offers a practical approach to the identification and management of targeted risk factors for child maltreatment for families with children aged 0-5, integrated into paediatric primary care. By addressing these problems, *SEEK* aims to strengthen families, support parents, and thereby enhance children's health, development and safety, while helping to prevent child maltreatment. Professor Howard Dubowitz created and runs the *SEEK* programme in Center for Families within the Department of Pediatrics at the University of Maryland School of Medicine, Baltimore. He has published extensively on the programme and has successfully continued to attract national and charitable funding for its continuation.



Entrance to the University of Maryland School of Medicine where the *SEEK* programme is managed.

The programme is extremely simple and comprises of a Parent Screening Questionnaire and parental handouts. It takes a multi agency approach by providing social work support in a proactive and non-stigmatising setting.

The Parent Screening Questionnaire (PSQ) is used to identify/screen (not diagnose) particular problems that are identified as common risk factors for child maltreatment including: maternal depression, alcohol and substance abuse, intimate partner (or domestic) violence, parental stress and difficulty coping and food insecurity (AppendixTwo). The PSQ is handed to parents at selected well-child visits for them to complete voluntarily while waiting, and then given to the health professional at the start of the visit at the 2, 9 and 15 months, and 2, 3, 4, and 5 year child development clinic visits. The opportunities to engage with parents are provided at the extensive development check schedule which includes 1, 2, 4, 6, 9, and 12 months in the first year. The checks extend throughout childhood and adolescence up to age 20years.

I observed one of the clinics which is staffed by Paediatricians. In the USA, Paediatricians are regarded as generalists rather than the specialist status they enjoy in the UK. In other centres, nurse practitioners carry out the assessment. The PSQ is on one side of A4 paper and is laminated so parents can complete it in the waiting area using a marker pen, after which it can be wiped clean for future use. If parents respond with 'yes' to any of the questions, health professionals are provided with guidance and a set of algorithms to prompt them to ask further questions and provide information re: support that is available using a motivational interviewing approach. If necessary, parents can see a social worker during that visit. If they do

not wish to engage at that point they can be encouraged to return or to accept written information.

As can be seen from Appendix Two, one of the questions on the PSQ is “Do you sometimes feel the need to hit or spank your child”. During my visit, a parent ticked ‘yes’ to this question and was happy to discuss it with the Doctor and she described the help she was already receiving and confirmed where else she could source support.

### **3.2 SEEK: The evidence base.**

The evidence base for SEEK has been published in a series of articles describing two randomized controlled trials. The first was conducted in a paediatric trainee primary care clinics serving a very low-income urban population and the second was in 18 suburban private paediatric practices serving a mostly middle-income and relatively low risk population. Both trials demonstrated significant improvement in the level of competency, comfort and ‘practice behaviour’ regarding how to address the targeted risk factors. The improvements were sustained for up to 36 months post training. (Feigleman et al 2011).

The first study showed significantly lower rates of child maltreatment in all the outcome measures: fewer Child Protective Services reports, fewer instances of possible medical neglect documented as treatment nonadherence, fewer children with delayed immunizations, and less harsh punishment reported by parents. Families with prior child welfare involvement were not excluded from the study sample, blending results for primary, secondary, and tertiary prevention (intervention) samples. (Dubowitz et al 2009).

In terms of time, the evidence from the studies highlighted that SEEK did not require additional time for health professionals to address psychosocial problems on average and this was supported in practice by the clinicians I spoke with. This is an important consideration for transferability to the UK as experience has taught me that efforts to introduce any interventions that add a substantial time pressure on clinicians will struggle to gain traction.

The second study included a cost data analysis which considered the price per child per year of the programme against the cost per case of incidents of physical abuse/assault. The authors summarised that “SEEK cost \$3.38 per child per year and \$210.20 per case of psychological aggression or physical assault averted” leading to a conclusion that expansion of the SEEK model in paediatric primary care could decrease health and social care costs associated with child maltreatment..

### **3.3 SEEK in the UK**

The programme of child development assessment in the UK is described in the ‘Healthy Child Programme (DH 2009 amended August 2010) and is cited in the NHS England publication “2015/16 National Health Visiting Core Service Specification” . The programme literature places a clear emphasis on parental support through a model of progressive universalism i.e. it includes a universal service that is offered to all families, with additional services for those with specific needs and risks. It describes the delivery of parenting support as (pg 10):

- Supporting mothers and fathers to provide sensitive and attuned parenting, in particular during the first months and years of life.
- Supporting strong couple relationships and stable positive relationships within families, in accordance with *The Children's Plan* (Department for Children, Schools and Families, 2007).
- Ensuring that contact with the family routinely involves and supports fathers, including non-resident fathers.
- Supporting the transition to parenthood, especially for first-time mothers and fathers.

There is no expectation that advice regarding coping with crying babies should be proactively provided and the emphasis is very much on discussing issues parents wish to raise:

“Temperament-based anticipatory guidance and listening to parents’ concerns. Examples of topics that parents may wish to discuss include: interacting with baby (e.g. songs and music, books); feeding, diet and nutrition; colic; sleep; crying; establishing a routine; safety and car seats; the immunisation programme; prevention of SIDS; changes in relationships; sex and intimacy after birth; contraception; and division of domestic chores.” (pg 41).

The only prescribed ‘visit’ following discharge by a community midwife is a ‘New baby review’ which should be a face to face interview with ‘mother and father’ by a health professional within fourteen days.

After that babies will be seen routinely in a clinic environment at 6 to 8 weeks for comprehensive physical examination and first immunisation (at 8 weeks), the second immunisation at 3 months, the third at 4 months and the HIB and Meningococcal C vaccination at 1 year. In terms of AHT specifically, the optimum time to provide the SEEK PSQ if it were to be delivered in the UK would be at the 6/8 week check.

### ***3.4 The New York Shaken Baby Prevention Programme and the Pennsylvania Shaken Baby Syndrome Prevention Programme.***

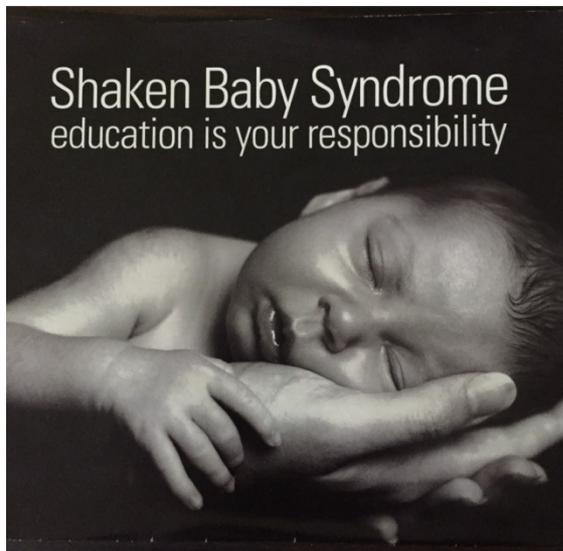
The Shaken Baby Syndrome Prevention and Awareness Programme was developed in 1998 in Upstate New York by Dr Mark Dias, Paediatric Neurosurgeon. The intervention includes education for all parents of newborns on the dangers of violent shaking and alternative responses to persistent infant crying. Since the inception of the SBS programme, Upstate New York has reduced the incidence of AHT injuries by nearly 50%.

In 2002, the identical programme was started as a pilot study in central Pennsylvania and Pennsylvania Law 2002-176: The Shaken Baby Syndrome Education Act was passed. The programme partnered with the Pennsylvania Department of Health and by 2006 became the first in the nation to provide consistent hospital-based education in 100% of all birthing and children’s hospitals in Pennsylvania.

In 2007 the Centres for Disease Control and Prevention (CDC) awarded the Pennsylvania Shaken Baby Syndrome Prevention Programme a grant to expand the programme into paediatric and family practice offices in 16 counties in Central Pennsylvania until October 2012. The CDC also provided funding for the development, production and distribution of the AHT video which is now being used in hospitals statewide.

Both programmes using the Dias Model are hospital based. Nurses discuss AHT with parents who are also shown a video, provided with a brochure and asked to sign a voluntary 'Commitment Statement' (Appendix Three) confirming they have received these elements of the programme. The signed Commitment Statements serve a dual purpose in being a physical affirmation of the parents' having received the message and to share the information they have learned with other care givers, as well as being a means of data collection.

A team of dynamic Nurse Co-ordinators (Kathy deGuehery in Upstate New York and Kelly Cappos in Pennsylvania) in both areas monitor progress of programme delivery within the hospitals and provide in-service training for new staff across what are huge areas. In addition, the Nurse Coordinators fulfil a research nurse function in supporting the data collection and analysis that feed into the wider research programme. The challenges of overseeing such a large area of programme coverage includes maintaining the integrity of the programme. My visits with Nurse Co-ordinators from both programmes showed how much of a challenge this could be. However, the regular production of quarterly newsletters and annual conferences on top of the visits helped maintain a corporate approach.



Poster circulated by Nurse Co-ordinator Kathy DeGuerhey to hospitals in Up State New York reminding them to deliver the Shaken Baby Syndrome Prevention Programme

My visit was reported in the Pennsylvania Shaken Baby Syndrome Prevention Program newsletter (Appendix Eight). Dr Dias was awarded a life time achievement award at the NCSBS 15<sup>th</sup> International Conference for his work. This is an example of the profile of work such as that of Dr Dias internationally.



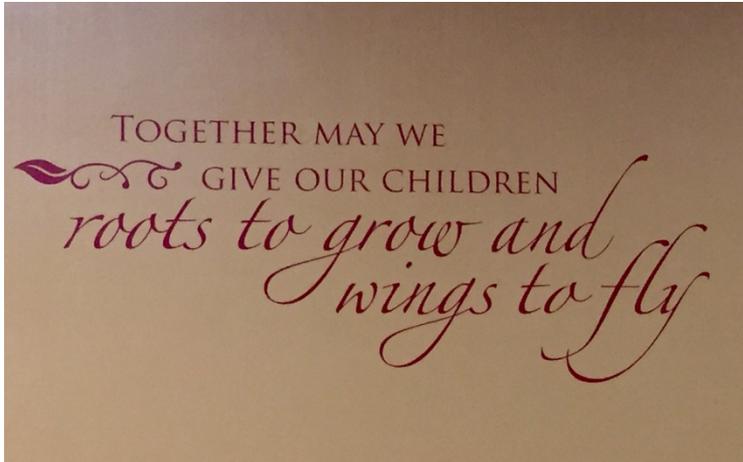
**Dr Dias receiving his life time achievement award at the NCSBS 15<sup>th</sup> International Conference on Shaken Baby Syndrome/Abusive Head Trauma.**

Left to right Mr Dave Cappos, Mrs Kelly Cappos (Nurse Co-ordinator for PA SBS Prevention Programme), Dr Mark Dias (Paediatric Neurosurgeon and founder of the Dias Model Prevention Programme), Mrs Anita Dias.

During my visit to Pennsylvania (Appendix Five) I visited the Pinnacle Health Children's Resource Centre and was shown round by manager Lynn Carson. The centre was created in 1994 to provide a central location for all agencies involved in evaluating and treating children suspected of being abused. It is also actively involved in educating the community at all levels about the existence of child abuse and to teach responsibility in and methods of reporting. The model of service provision is not replicated in the UK to the same degree and during my Travel Fellowship I visited two other such centres in Montana and Kansas and found them inspirational places that provide a level of community, family and child support that is shown to make a difference. As the Pinnacle Health Children's Resource Centre literature describes:

"The single most important factor affecting a child's recovery [from abuse] is the level of support the child receives from the parent or caregiver. Research indicates that primary caregivers who are supportive can offset the negative impact of abuse. Furthermore, children who feel supported are more likely to maintain a higher level of interpersonal, academic and social functioning...Providing support cannot only rest with services to the child victim, but must extend to providing care and support to parents and caregivers as well".

As part of the aim of my Travel Fellowship is understanding the wider context of the delivery of care and the systems and processes in which they are provided and commissioned, I feel this model is something that should be given serious consideration in the UK and is discussed later in this report.



One of many quotations on the walls at Pinnacle Health Children's Resource Centre that sums up the ethos of the place.

### ***3.5 Dias Shaken Baby Prevention Programme: the Evidence Base.***

Dias et al (2005) completed a study in which all 16 hospitals providing maternity care in an 8 county region of Western NY State served by Buffalo Women and Children's Hospital, participated. The programme was administered to parents of all newborn infants before the infants were discharged from hospital. Hospital provided mothers and fathers/father figures with information describing the dangers, alternate responses to persistent infant crying and to have both parents sign a commitment statement (CS) affirming their receipt and understanding of materials.

The programme compliance was assessed by documenting the number of CS signed. Follow up telephone interviews were conducted with randomised 10% subset of parents 7 months after the birth to assess their recall of the information.

The regional incidence of AHT in babies less than 36 months of age during the programme was compared with the incidence during the 6 preceding years (historical control group) and with the statewide incidence rate for the Commonwealth of PA during the control and study periods.

Results: During the first 5.5yrs, 62,205 CSs were documented representing 69% of 94,409 live births in the region. Signatories were:

- 96% signed by mothers
- 76% signed by fathers/father figures

The follow up calls 7 months later suggested that over 95% of those contacted remembered having received the information. (Information isn't given about what proportion of those calls reached men.)

AHT decreased by 47% from 41.5 cases per 100,000 during the 6 year control period to 22.2 cases per 100,000 during the 5.5 year study period. No comparable decrease was seen in the Commonwealth of PA.

The findings led to a conclusion that a co-ordinated, hospital based parent education programme targeting parents of all newborn infants can significantly reduce the incidence of abusive head trauma in children less than 36 months.

A further study by Altman et al (2010) supported this conclusion demonstrating a decrease from 2.8 injuries/year to 0.7 injuries/year represents a 75% reduction.

A total of 53.6% of parents who completed the questionnaire agreed to be contacted in 6 months for follow up telephone interview.

- When asked whether they remembered receiving information about 'how to care for your baby if he/she cries a lot' 88.4% of parents said 'yes'.
- When asked whether they specifically remembered watching a video about shaking injuries 97.8% said 'yes'.
- When asked whether they could think of any situation in which the infant cried a lot and the educational information was helpful, 55.6% said 'yes'.

The authors highlighted that it is not possible to be absolutely certain that the educational programme was the cause of the decrease and discussed how uncertainty about the cause and effect relationship is an inherent limitation of before/after study design. However, they were able to demonstrate absence of changes over time in 3 nearby states without similar prevention programmes which lends support to a cause/effect interpretation.

Crucially, the authors drew attention to the fact that fathers and male surrogates are nearly 5 times as likely as mothers to shake an infant. From the parents surveyed only 40.4% of fathers watched the educational video. Finding better ways to reach male caretakers should be a priority.

### ***3.6 Dias Shaken Baby Prevention Programme in the UK.***

At the point of undertaking my Travel Fellowship, the NSPCC were in the process of evaluating their 'Coping with Crying' video. The NSPCC pilot was completed in 3 phases including community antenatal programme intervention, hospital based intervention and community post natal intervention. Coster et al (2016) have now completed their evaluation and the conclusions summarised on the NSPCC website as:

- The highest proportion of parents saw the film when it was shown at routine clinic appointments or in the hospital after having given birth.
- Nearly all parents remembered seeing the film up to 6 months after they had watched it.

- Parents who watched the film in hospital after the birth reported a small improvement in their knowledge about infant crying and the dangers of shaking their baby, as well as their use of new coping strategies.
- The film had more impact on parents who watched the film in the antenatal or postnatal period, after discharge from hospital, than parents who had watched it in hospital. They had better knowledge about the impact of shaking their baby, were more likely to agree that it was normal for babies to cry, used the recommended soothing strategies more often and felt more confident asking for help.
- Evidence suggests that during times of stress parents who had watched the film were reacting in a positive way to their infant crying and were seeking help when it was necessary.
- The evaluation did not find any evidence that the babies of parents who watched the film had fewer injuries than the babies of parents who had not watched it. However it is difficult to measure this because parents were asked to report all injuries that their baby had sustained, not just those which were non-accidental.

In terms of reach to fathers and male surrogates, Coster et al (2016) findings support that of Dias and Altman showing an 87% reduction in men watching the film in the community post natal pilot compared to the hospital pilot and 75% reduction in men watching in community ante natal pilot. There is an emerging theme of a trade off between impact and reach. The best impact is in the community but the best reach is in hospital. However, all studies agree that a higher percentage of men are present in the hospital setting than in the community. The man who is seen in hospital may not be the same man that is caring for the child at 6 weeks which is why the emphasis on sharing the information with other care givers is crucial. The graphics used in the NSPCC video are almost identical to those used in the Dias video.

### ***3.7 The Period of PURPLE Crying***

The Period of PURPLE Crying programme is the name given to the National Centre on Shaken Baby Syndrome's evidence based AHT prevention programme. The aim of the programme is to support caregivers in their understanding of early increased infant crying and to reduce the incidence of AHT. The programme materials comprise a colour 10 page booklet, a parent reminder card, a 10 minute 'PURPLE Crying' video and a 17 minute 'Crying, Soothing, Coping: Doing What Comes Naturally' video. The materials are intended to be given to all parents of new infants.

The acronym PURPLE stands for:

- Peak of crying – baby may cry more each week, the most in month 2 then less in months 3 – 5.
- Unexpected – Crying can come and go and you don't know why.
- Resists Soothing – baby may not stop crying no matter what you try.
- Pain-Like Face – A crying baby may look like they are in pain even when they are not.
- Long lasting – crying can last as much as 5 hours a day or more.
- Evening – your baby may cry more in the late afternoon and evening.

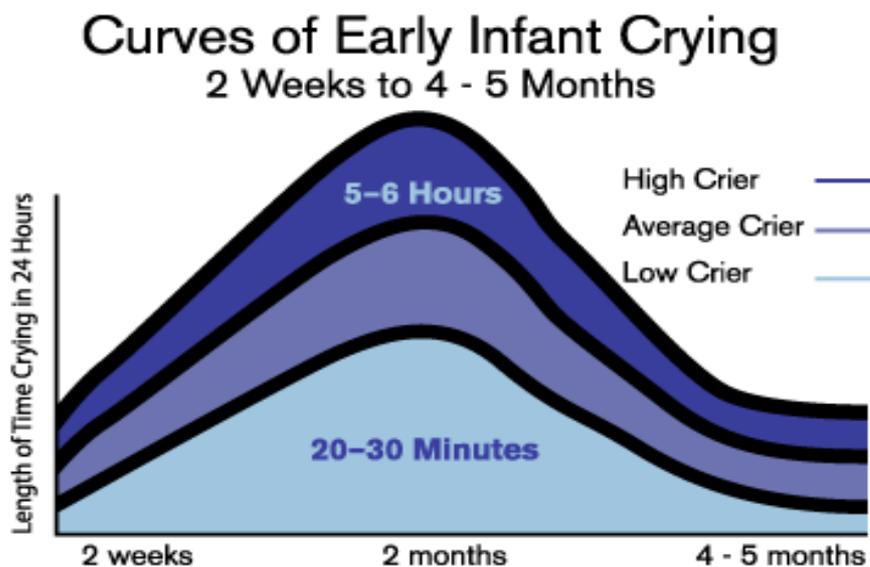
The word 'period' means that the crying has a beginning and an end.

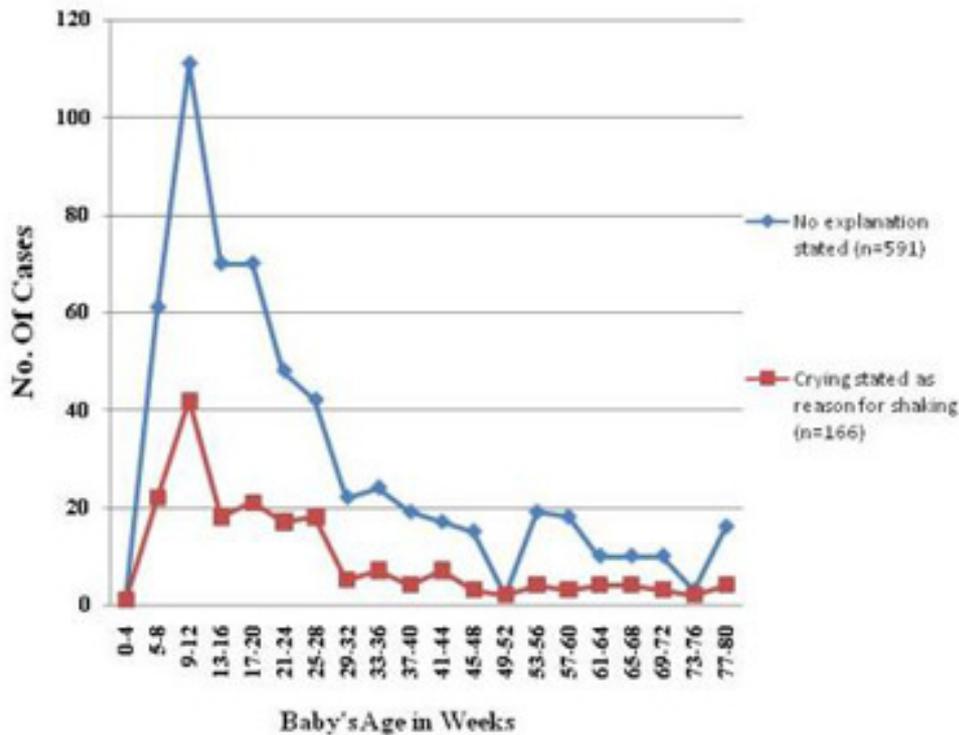
The programme operates on a 'three dose model':

- Dose one – delivery
- Dose Two – reinforcement
- Dose Three – public education.

The programme literature highlights how "... prevention partnerships across organisations and jurisdictions allow for all three doses to be implemented." The fidelity of the programme is maintained through a very structured implementation protocol and fidelity agreement and is monitored closely through the National Centre of Shaken Baby Syndrome based in Utah.

One of the key concepts of the programme that has been thoroughly researched over 30 years, is the notion that infant crying is a normal behavioural development but has been interpreted clinically as something wrong with the infant, the infant's caregiver, or the interactions between them (Barr 2012). Barr's research shows a demonstrable relationship between the normal peak of crying and babies subject to AHT (graphs reproduced with kind permission of Period of PURPLE Crying programme).





I visited 3 sites where the programme was implemented including Vancouver, British Columbia, Helena, Montana and Wichita Kansas. The programme was at different stages of delivery and had varying levels of success and different challenges at each site which provided a fascinating insight into what makes a programme successful which will be discussed in more detail in section 4.

The delivery of PURPLE in Vancouver was so embedded that when I discussed it with maternity managers in the British Columbia Women and Children’s Hospital staff were unable to recall a time when the programme was not delivered. It was part of the culture and practice of that hospital there was no real concept of providing maternity care without the programme in place.

### **3.8 PURPLE: The Evidence Base**

The PURPLE programme is underpinned by Barr’s substantial research over 30 years into infant crying behaviour. The program has completed randomized controlled trials and in 2003-2006 the NCSBS, the Harborview Injury Prevention and Research Center of the University of Washington, and the University of British Columbia conducted parallel trials in two countries, Canada and the United States. New materials including an education video and booklet were produced as a result of collected data. These trials successfully determined that the messages in the materials resonated with parents and could change their knowledge and behaviour. The program was tested through four different types of delivery systems: maternity services, paediatric offices, prenatal classes and nurse home visitor programs. More than 4,400 parents participated in the research and 75 parents in two countries participated in focus groups to develop the programme materials. The research results were statistically positive and the programme made available.

Research continues and in 2015 Barr et al published research aimed at determining whether there was any change in visits of 0- to 5-month old infants to the medical emergency room (MER - known as the Emergency Department in the UK) of a metropolitan paediatric hospital after province-wide implementation PURPLE. Results showed that before the program, crying case visits represented 724 of 20,394 MER visits (3.5%). The age-specific pattern of MER visits for crying peaked at 6 weeks and was similar to the previously reported age-specific pattern of amounts of crying in the community. After program implementation, crying cases were reduced by 29.5% ( $p < .001$ ). The most significant reductions were for crying visits in the first to third months of life. The authors concluded that the findings imply that improved parental knowledge of the characteristics of normal crying secondary to a public health program may reduce MER use for crying complaints in the early months of life.

It was an honour and a privilege to be given the opportunity to present my work at BC Children's Hospital as part of my visit.

**Evidence to Innovation**  
*Research In Progress Series*

“Learning Lessons:  
Prevention of Abusive Head Trauma  
(AHT) in Infants”  
Dr. Suzanne Smith

Wednesday November 2, 2016 | 12:00-1:00 PM  
Room 3113  
BC Children's Hospital Research Institute

### **3.8.1 PURPLE in Wichita, Kansas**

PURPLE was implemented in Wichita and co-ordinated through the Kansas Children's Services League's Child Abuse Prevention programme.

The selection and implementation of PURPLE was part of the Community Awareness Work Group. Involved were early childhood community, hospitals, law enforcement, Health Department agencies, universities, school districts, child welfare, mental health agencies, domestic violence staff and directors, legislators

and community members. Professionals from community and hospitals were invited to attend training together and for some it was the first time they had met each other. The project started breaking down silo walls between agencies.

Universities put PURPLE into their pre-service curriculum for Nursing, Social Work and Medical School residents. Wichita School Resource Officers taught Elijah's story, a video produced by NCSBS, in a one and a half hour block to every high school senior in every private and public school.

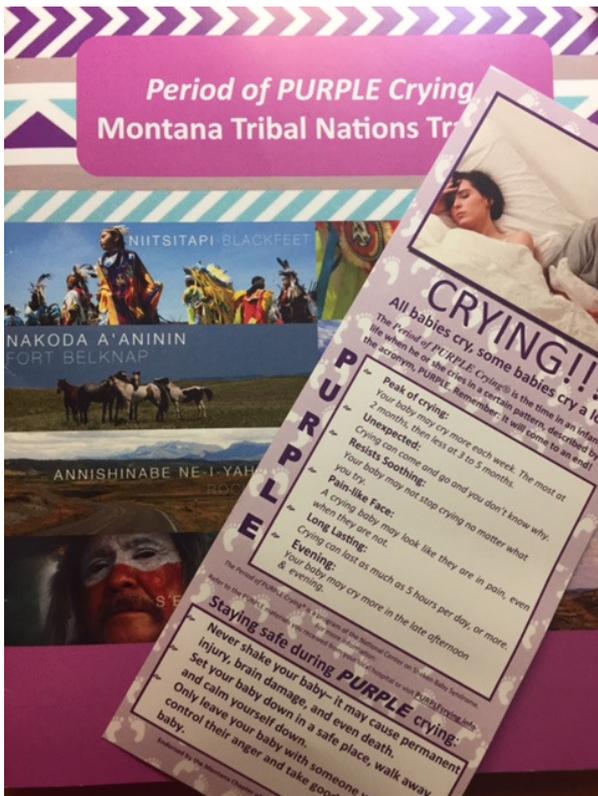
Funding sources included insurance companies and banks. The normal agreement with funders was for them to fund 100% in the first 2 years then 50% in the 3<sup>rd</sup> year then the funding would stop so the need to be constantly applying for funding was clear. The Wichita Public Schools Family and Consumer Science Classes implemented the teaching of PURPLE into their curriculum. KCSL sent out quarterly Constant Contact messages with updates to funders and programme implementers. The 'Bikers Against Child Abuse' group held PURPLE nights at the Wichita Thunder Ice Hockey games.

Wichita went from 8 child abuse fatalities in 2008, to 2 in 2009 to 1 in 2010 to none in 2011, 12 and 13. The figure is starting to climb again since 2014 and efforts are being made to understand the reasons. However, they have not reached the levels they were at in 2008.

### ***3.8.2 PURPLE in Helena, Montana.***

Since 2009 Montana joined 23 other states in including AHT related mandate as part of State Law. PURPLE was selected for use in Montana in 2011 and was funded by the Children's Trust Fund from March 2012 to July 2015 through grants to the organisation Healthy Mothers Healthy Babies (HMHB). A comprehensive analysis of progress was undertaken in November 2015 by an independent consultant who concluded that during the first three years of funding, the PURPLE Montana initiative led by HMHB lacked strategic direction and public health understanding. The report highlighted that as a result only 12 hospitals were recruited during the 3 year funding period and only Dose 1 had been implemented with no plans to implement doses 2 and 3. However, the report suggested that the year 4 application showed a strong understanding of what was needed in Montana to improve the implementation and advance doses 2 and 3. The report also highlighted the challenges of staffing and board changes at HMHB during the 33 month period which saw 3 different executive directors and a staff turnover of less than 20 months.

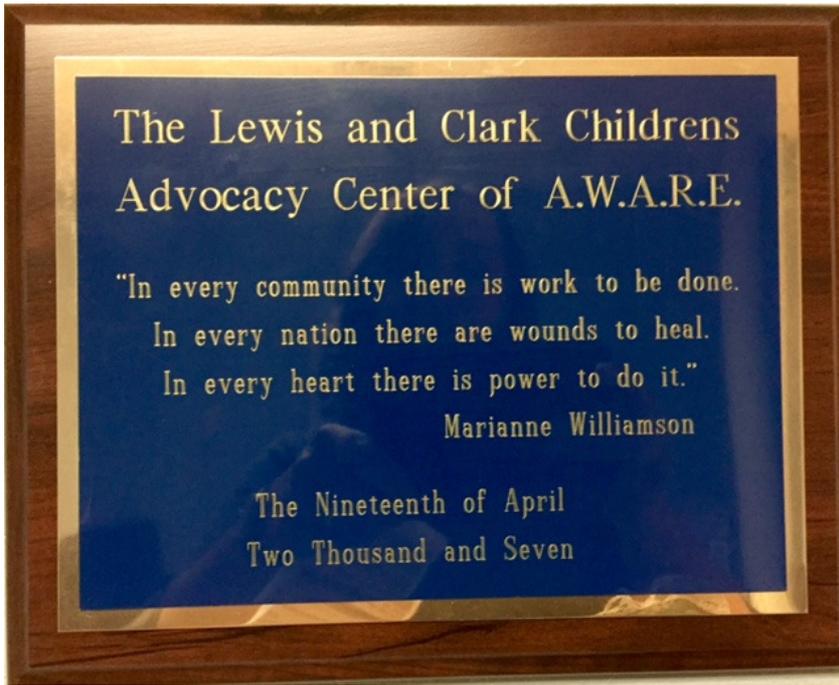
A few weeks before I was due to fly to Montana, I learned that the funding for the programme had been cut. However, the staff at HMHB were determined to continue the implementation of Dose 1.



Materials at Healthy Mothers Healthy Babies in Montana are adapted to reflect the diversity of the population.

### 3.9 Lewis and Clark Child Advocacy Centre

As part of my visit I spent some time at the Lewis and Clark Child Advocacy Centre (CAC), a similar facility to the Pinnacle Health Children's Resource Centre and Kansas Children's League Services. Children seen at the CAC are victims of physical abuse, sexual abuse and children who have witnessed violence such as domestic abuse and AHT. The Centre manager discussed with me the means by which the funding for the centre is maintained. She explained that the payment per child system leads to arguments and discussions about whether to send a child to the CAC. She finds that Child Protection Services will then try to dictate the intervention using the position that they are paying for the service for that child and seeing themselves as a purchaser rather than a commissioner of a service. The position as commissioners would be aimed more at the CAC deciding what the child needs based on their in depth assessment. Fears that the focus and experience of the child get lost amid funding disputes are very real. However, the CAC provides a strong leadership in avoiding that loss of focus.



The plaque outside the Lewis and Clark CAC.

## **4. Findings: Funding and Infrastructure and successful implementation**

### **4.1 Funding**

It became very apparent to me that the same challenges to secure funding for public health and prevention initiatives is as prevalent in the areas that I visited as it is in the UK. The need to embed a programme into a well established organisation where the search and capture of grants and funds is part of its infrastructure is essential. This was especially apparent in the comparison between PURPLE in Montana and in Kansas. The instability of the workforce in Montana and the delay in achieving effective grip with the programme certainly had an impact on funding decisions. HMHB is a small organisation in comparison the KCSL in Wichita.

KCSL has its roots in two parent agencies: Kansas Children' Home Society founded in Topeka and the Christian Service League founded in Wichita. Both agencies concentrated on finding permanent homes for orphaned or abandoned children and foster homes for children whose parents were temporarily unable to care for them. The two agencies merged in 1926 to continue its tradition of providing direct services to children and families and advocating for policy changes to help families and children. By the 1970s, societal changes led to decreases in the number of babies placed for adoption. In response, KCSL developed a broader range of services to meet the changing needs of children and families.

Today, KCSL services and advocacy efforts focus on preventing child abuse, strengthening families and empowering parents and youth and describes itself as a Family Resource Centre. It provides services and describes services within the 3 levels of public health prevention and intervention; primary, secondary and tertiary. The detail of the programmes delivered are found in Appendix Four.

The provision of a range of programmes funded from a variety of sources and complimenting each other allows flexibility for the organisation to support programmes at a primary preventative level that may take some time to show effectiveness as is common with early help initiatives. The alignment of the programmes with the public health levels of intervention is particularly powerful as it shows how they feature as part of a wider public health continuum achieving a sense of connectedness in order to support children and families in a wrap-around, holistic manner.

Planning ahead to source funding year on year is also extremely important. None of the places visited on my Travel Fellowship assumed funding would be automatically renewed. Evaluation is built into all the programmes from the beginning and research continues throughout with an eye to attract funding when the current funding stream runs out. The current leadership at HMHB in Montana is acutely aware of this and employs a senior manager whose job it is mainly to seek out funding sources and present a case for continued funding.

### **4.2 Leadership and passion**

Knowledgeable and effective leadership must drive programmes in order for them to be successful and reach as many areas as possible. The overwhelming success of

the Safe Babies New York programme and Shaken Baby Syndrome Prevention Programme in Pennsylvania in terms of reach and response can largely be attributed to the programme creator, Dr Mark Dias and the Nurse Co-ordinators in each area. Despite the scale of the challenge in terms of population size and geography the outputs from the Pennsylvania programme alone are staggering. A small sample of these include:

- Tracking and maintaining hospital compliance at 104 facilities achieving 91% return rate of commitment statements in 2015 (130,277 out of 143,188 births).
- Troubleshooting issues at hospitals and providing support through emails, quarterly newsletters, phone calls, website postings, in-person staff training and management meetings with between 10 – 45 contacts per facility per year.
- Providing training to 566 nurses at 39 hospitals.
- Presenting at conferences, community events at 19 venues to 1410 attendees.
- Hosting an international conference.

#### ***4.3 Adapting the message and the delivery: keeping it flexible***

It is clear from all the programmes that the vision, the message and the implementation has to be constantly revisited, highlighted and refreshed to keep professional interest alive, to keep the materials contemporary and to stop the topic slipping below funders' and legislators' radars. For example, the Buffalo programme now includes reference to the 'Safe Sleep' message. Combining resources (mainly time) to deliver the AHT and safe sleep messages at the same time will prevent one message having precedence over the other or one campaign putting itself in competition against the other.

The same opportunistic and forward thinking combination of messages was presented at the conference in Montreal by the Safe Baby Plus team in Florida. The programme has its roots in the Dias Model and is supported by Dr Dias and his team. The main messages in this programme are focused on:

- Choosing a safe caregiver
- Preventing AHT
- Promoting Safe Sleep.

Parents are encouraged to use a 'safety zone' model to choose safe caregivers for their child. The same message about learning how to cope with the crying rather than trying to make it stop when all soothing techniques have failed is central to the programme as in the other programmes I visited. The addition of the 'Help Me Cope' action plan is also a feature of the other programmes.

Asphyxia from bed-sharing is one of the 3 causes of preventable death in Florida. This finding resonates with the Pennsylvania Child Death Review findings which I discussed in detail with during my Travel Fellowship with the Child Death Review team from Lancaster County . This is a persistent finding from the Child Death Overview Panels in Greater Manchester and the attraction of including the AHT Prevention message with Safe Sleep education seems sensible.

During my visit to Kansas, I went to see the Executive Director of the Kansas Crib for Kids programme which focuses on the safe sleep message and provide safe travel cots and wearable baby blankets to new parents. The programme is grant based and the organisation write grants or help hospitals and health departments write grants to provide free cots to their parents who have no other resources to acquire a cot. The need to combine both messages was reiterated and felt to be an entirely normal progression. KIDS concentrated on getting the safe sleep message out before people have purchased a cot so that new parents to be can make safe choices. The message about safe sleep is then repeated at different points in the early weeks and months of a child's life. The challenges of the political environment were clear for grant based programmes like this.



Executive Director, Christy Schunn demonstrating the safe sleep travel cots that are distributed to new or expectant parents who have no resources to acquire a cot.

A meeting with the Paediatric Manager at Wesley Medical Centre in Kansas highlighted methods of ensuring staff keep on board with the AHT message i.e. PURPLE. Reminding staff of the importance of completing the surveys was planned to be done as part of the ward huddles. The KIDS safe sleep message is delivered in hospital and the travel cots/bassinets are provided as per programme.

Different methods of capturing the PURPLE information is under consideration e.g. using Ipads, Survey Monkey, creating a hybrid Dias and PURPLE monitoring form. Mark Dias is in the process of exploring the use of text messaging to reinforce the message and also complete surveys. This has resonance with my experience in my employing Trust and the different methods that are explored to capture 'Friends and Family Test' data. Our experience tells me one size does not fit all and keeping data collection flexible but consistent is vital.

#### **4.4 Measuring**

Despite the successful statistical evaluations in the New York programmes, the Pennsylvania State funding will cease in 2017. Recent figures have not been able to show that the programme reduces the incidence of AHT. This raises questions about funders requiring a single metric as a measure of success. The degree to which the incidence might have been higher had the programme not been in place cannot be ascertained without deep dive case studies and exploration of the cases

that have been reported having received the programme or not. In addition the limitation of before and after studies will always be that they cannot prove cause and effect especially with regard to such multi faceted and socially constructed phenomena as child abuse.

However, other measures of success can be usefully considered such as the rates of crying babies attending EDs before and after initiation of the programme, the degree to which parents recall the information provided and use the materials etc.. Although different measures are used for the Dias Model, the funders seem to focus only on the incidence. The challenge of influencing how much value external bodies place on qualitative data and data that measure behavioural change is burgeoning. This point was made strongly by Mary Clyde Pierce MD, Northwestern University, at the NCSBS 15<sup>th</sup> International Conference on Shaken Baby Syndrome/Abusive Head Trauma in Montreal. Mary maintained that maths is determining whether studies and interventions are valid or not. Although she was applying this to diagnosis and the need for clinicians to be allowed to rely on their interpretation of history and physical analysis rather than computational models, the underlying point is the same 'sometimes the maths is wrong'.

#### ***4.5 Political drivers***

The political landscape has a bearing on programmes that are likely to be adopted and the need to ensure that research and narrative can speak to the current political and socio economic landscape is important. It was clear from some of the places I visited that funding decisions were influenced by elections and changes in administration locally. This was particularly the case in Montana in relation to PURPLE and in Kansas in relation to the KIDS safe sleep programme.

The public health link with social policy and, in particular, poverty is as prevalent in the debate about crime as it is about AHT.

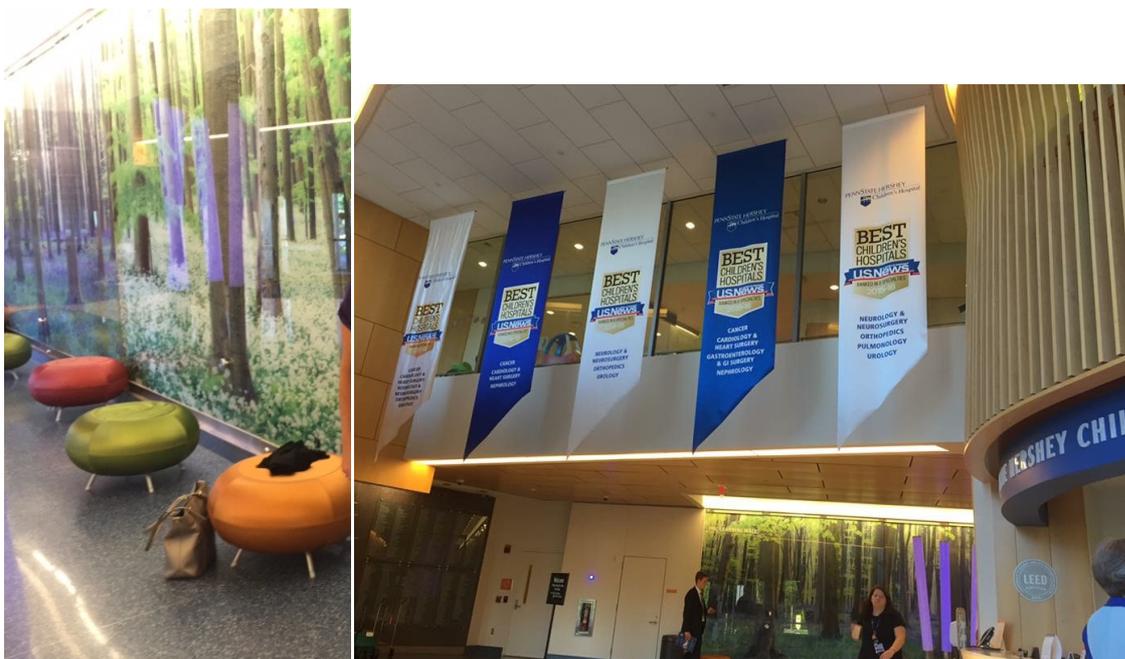
## 5. Travel to learn, return to inspire: Relating findings to the UK.

I expected to find significant differences in the nature of challenges and dilemmas facing health and social care professionals in the USA and Canada than in the UK. However, I was struck by the degree of similarity.

I learned from the Director of Nurse Practitioners and Physician Assistants at the University of Maryland Medical Centre that recruiting and retaining nurses in the US is as much of a challenge as in the UK. I also learned that the ‘patient experience’ agenda is not as well engaged with regard to the experience of children and young people as in my Trust in the UK.

In Vancouver, I discussed the challenges of ever increasing demands on the health service to cope with long term conditions and the lack of increasing capacity in social care to discharge people to safe caring environments which places significant pressures on acute services and Emergency Departments. It was emphasised to me that the same concerns faced the health service in British Columbia.

Some facilities I visited were breath taking in terms of their appointment, art work, rest and play facilities, parent support facilities such as the entrance to Penn State University Children’s Hospital in Hershey.



The impressive entrance to Penn State University Children’s Hospital in Hershey.

However, some facilities were as downtrodden and tired as some NHS provision in the UK. As with the UK, the difference seemed to relate to access to charitable and private funding. Overall, I felt proud that the NHS in the UK stood up to scrutiny next to USA and Canadian health care facilities.

In terms of public health, the safe sleep concern is as prevalent in the US and Canada as in the UK. At Wesley Medical Centre in Kansas, I spoke to a Nurse

Manager who was of the impression that the safe sleep message was given precedence over the AHT message. The danger of this happening had been recognised in Florida and in Buffalo which I learned through the conference presentation (Florida) and my visit (Buffalo) and was the reason why the AHT and safe sleep messages were combined. I feel that the same dilemma would be very much the case in the UK and this has helped shape my programme recommendation.

At the NCSBS 15<sup>th</sup> International Conference on Shaken Baby Syndrome/Abusive Head Trauma in Montreal I was struck by the degree to which families affected by AHT are supported and brought into the education agenda as peer educators and supporters. I am in touch with a group of people through a charitable foundation called 'Charlees Angels' who have been affected by AHT. I have explored whether they wished to inform and shape a campaign and asked if they wanted to hear about my visit and 15 people have been in touch keen to be part of a prevention campaign. The value of involving families in this way is not simply for the benefit of a campaign but is also a route through which they can come to terms with their tragedy. One parent told me that it is hard for her to access traditional bereavement groups because when others learn how they lost their child, they feel judged by others who cannot understand how they did not recognise the risk their partner presented. In fact, I was the only person this parent had spoken to freely who had nothing to do with social care or the police.

As part of my Fellowship I visited an inspirational bereavement centre called 'Highmark Caring Place'. The Outreach and Education Coordinator and child grief specialist discussed the work they did with children and families and especially children of all ages and stages of development, to help move through their journey of grief. This had resonance with me after speaking to the families affected by AHT. The grief pertains, not only to the child who has died, but also to the child who has suffered severe brain injury because there is still a sense of grief at the loss of function, ability and opportunity the child would have had.



Kelly Cappos, Me and Terri Bowling, Child Grief Specialist, in front of the poignant tree containing names of all the children being remembered at Highmark Caring Place.

The applicability of the Dias Model in the UK presents some immediate challenges. As the programme is hospital based time is required to show the video prior to discharge of the mother and child. The provision of community midwifery and health visiting services in the UK allow for discharge of mother and baby to be as early as 6 hours after birth. In Canada and the USA, the minimum stay is generally 24 hours. A 6 hour expected time of discharge leaves little opportunity to effectively deliver health promotion messages to any depth. However, there is an opportunity to introduce the topic that can be reinforced in the community.

After learning about PURPLE in Vancouver, I felt there might be a possibility of simply purchasing the programme. My main concern was about the applicability of an American based programme in the UK. However, after watching the videos I felt this would not necessarily be an issue as there were very few overt 'americanisms'. I met with the Mrs Marilyn Barr, creator and CEO of National Centre of Shaken Baby Syndrome (NCSBS) and Dr Ron Barr who has extensively researched infant crying and who developed the Period of PURPLE crying programme. I suggested the possibility of purchasing the programme and bringing it to the UK. They were of the opinion this could not be done and was contrary to NHS policy but I was able to reassure them this was not the case.

I asked about whether we could re-record the video using English parents but this was not accepted. Understandably, the programme has emerged from and been subject to decades of research and there is a determination to preserve programme integrity and fidelity. If the programme was to be adopted in the UK it would be subject to a significant amount of control and oversight from NCSBS. This could potentially be a limitation to the introduction of the programme in the UK as a degree of flexibility may be necessary. I informed Marilyn and Ron Barr, that I would hold a series of focus groups with professionals, parents and families affected by AHT to explore the degree of read across to the UK.

The points at which the programme is delivered fits extremely well with UK universal health care provision (Vancouver has home visitation programmes). Although the materials recommend showing the DVD prior to discharge, it can be shown in the community and a '3 minutes script' is provided for delivery in hospital. A 3 minute script feels far more achievable in the UK maternity setting.

The price of the programme worked out at £1.60 per baby. In NE Manchester there are 10,000 births a year. £16,000 a year would equate to one Serious Case Review so if the programme prevented one case of AHT a year it would have paid for itself as the average Serious Case Review costs between £15 – 20K as minimum.

The materials that come with PURPLE are relevant to all parents and caregivers and are aligned with UK public health messages including those relating to safe sleep. I have provisionally shared a few ideas and materials to the families group in the UK and in presentations I have already delivered and there is a very positive response to the nappy bag tags that were trialled in Buffalo as part of the Dias model and the leaflet that is part of the PURPLE package.

'Dose 3' of the PURPLE programme involves public awareness raising. This manifests itself in a variety of formats the most consistent being the 'click for babies'

campaign. This involves local knitting groups and members of the public knitting or crocheting purple hats to be given to every newborn as they leave hospital. Of course, the hats are purple and is intended to remind parents of the PURPLE education they have received and the materials. In addition, those who are doing the knitting become aware of the campaign and can share their knowledge with their family. Where this sounds a straightforward community project I saw how resource intensive it can be. Individuals and groups are provided with clear instructions/patterns for the hats but well meaning members of the public like to put their own take on it so sometimes the hats are the wrong size/colour or include ribbons etc.. On receipt of the hats, they have to be sorted with some hats going in the reject bin. They then have to be washed, sorted again, boxed up and distributed. I helped sort 3000 hats in Wichita and felt this would require additional resource if it were to become a feature of a UK campaign.

One of the most striking differences between the UK and US/Canada is the provision of Child Advocacy Centres/Resource Centres. I visited three Child Advocacy/Child Resource Centres as described earlier in the report, and was struck by how children who have suffered abuse can access counselling and treatment at the same time as providing evidence and undergoing clinical examination. A similar provision is available in the UK but only for children who have suffered from sexual assault/abuse. In Hershey I met with Dr Kate Crowell who leads a project called Transforming the Lives of Children (TLC). TLC provides therapeutic care for children in foster care following abuse. The care includes psychiatric care and trauma focused therapy. Children can be seen within a week of being seen in hospital. The waiting list for the equivalent of Child and Adolescent Mental Health Services (CAMHS) is 6 months to a year. The same challenges accessing CAMHS for children and young people present in the UK as they do in the US. Drawing this provision into wider programmes seems to be part of the solution.

An example of one institution that has maximised child centred provision across the public health spectrum is the Kansas Children's Services League. Their programmes include:

Primary (universal) prevention strategy:

- Parent helpline (staffed by home visitors and volunteers 24 hours a day)
- Community Resource Library (includes parental 'tip' cards).
- Period of PURPLE crying (Abusive head trauma education).
- Governor's Conference on the Prevention of Child Abuse and Neglect.
- E-learning training opportunities (human service professionals).
- Child abuse prevention month activities.
- Parent leadership conference
- Child abuse and neglect prevention training.
- Darkness to Light training (CSA prevention).
- Fatherhood
- Wichita coalition for child abuse prevention.

Secondary (targeted) prevention strategy:

- Head Start
- Early Head Start/Kansas Head Start,
- Healthy Families America/Home visitation
- Parents Helping Parents support groups
- Parent training
- Fatherhood groups
- Supporting school success/case management,
- Outpatient Mental Health
- Crisis Nursery/Case management
- Kinship Navigation.
- We're Family.

Tertiary (Selected) Prevention Strategy:

- Adoption search,
- Adopt Kansas Kids/Clicks for Kids & Kansas Post Adoption Resource Centre
- From Heart to Home Infant Adoption.
- Compass Resource Families & TIPS-MAPP (foster parent) training.
- Strong and Stable Families
- Drug Endangered Child/Case Management.
- Centre for Restorative Education.
- OASIS Runaway Youth Case Management
- Juvenile Intake Assessment.

These fall within the key thematic areas of KCSL of preventing child abuse, strengthening families and empowering parents and youth. The work of this place I found inspirational. The challenges relating to ensuring available funding are discussed above. UK Children's Centres have some resonance with KCSL but rarely match the breadth and depth of service provision and are now at risk of disappearing completely. I feel the KCSL model of service delivery is aspirational for the UK and something I hope can be explored.



The entrance to Kansas Children's Services League.

## 6. Making it Happen:

The learning and experiences gained through the programmes and people visited during my Travel Fellowship has informed the proposal for a prevention programme that impacts on all points of the public health spectrum. Using a similar coordinated approach to KCSL my proposal is a multi disciplinary approach to delivering the four key messages that all the programmes incorporate and including the crucial message based on Barr's research that crying is normal. The four point message is:

- Infant crying is normal and it will stop.
- There are comfort methods you can use that will sometimes sooth the baby and the crying will stop.
- Sometimes the soothing methods won't work and the crying can get to you. If this happens check your baby is safe - then walk away.
- Never ever shake or hurt a baby.

This four point message form the basis of a coordinated programme that involves all agencies and requires minimum intervention to deliver them as part of a light touch intervention, which I have referred to as a 'touch point'. Each 'touch point' is brief but reinforces the four main messages. The most co-ordinated part of the programme is the hospital based to age 6 week and can also incorporate simple 'safe sleep' messages. The programme I recommend is a staged prevention programme that could be initially implemented across a 24 month period and would be aligned to initiatives such as the 'Starting Well' initiative in Greater Manchester. An outline of the programme is:

### 6.1 *Primary Prevention (before a problem starts).*

- School based education: targeting boys, highlighting how a baby crying can be annoying and frustrating, teaching coping methods and emphasising never to shake a baby.
- Hospital based intervention: after delivery when discussing safe sleep, introduce what to do when there is no sleep and the baby is crying inconsolably. This can

be as short as a 3 minute 'script' and could possibly be delivered by trained volunteers. At this time a DVD can be provided or an app downloaded depending on the materials agreed.

- Post natively: midwives will normally discharge at around 10 days before the normal crying peak increase begins. Reiteration of the key messages can be given at discharge by the midwife and followed up by the health visiting team but not as part of the birth visit or the information will get lost. A specific visit which looks at safe sleep and coping with crying should be arranged by one of the Health Visitor (HV) team. The video that was provided in hospital could either be revisited or a discussion take place around the messages. This would take no more than 30 – 45 minutes.
- At the 6 week check in the GP surgery, a brief 'yes/no' questionnaire can be provided to parents in the waiting room. When they see the GP, any question that is ticked 'yes' will be a prompt for discussion and the opportunity for advice given and messages about coping reinforced which can then be followed up by the HV in clinic. The normality of the crying and the fact that the end is in sight will be a key message for this touchpoint.
- Awareness raising public health campaign: The background to this individual activity will include an outward facing population focused public health campaign that should be informed by groups of parents. An innovative campaign that speaks to the population of Greater Manchester would help embed the message and remind people of the programme. Ideas for the outward facing campaigns include a message included on baby vests, a projection of the message on buildings, nappy bag tags which inform the caregiver/childminder about how to cope with crying and to contact the parent if they are struggling to cope, video playing in GP surgery, A/E, outpatients etc..
- Community educators: families who have been affected by AHT are sometimes the best people to speak to parents about the dangers of shaking and the need to manage coping. In addition, many of them will be key in emphasising the messages should be shared with all the babies' caregivers.
- Fatherhood summits/cafes and parent cafes that may be hosted at Children's Centres or Voluntary Sector organisations.

## **6.2 Secondary prevention: intervention in the early stages of an emerging problem. Reiteration of messages in response to:**

- Identified stressors with families who have babies e.g. families in poverty, overcrowded, previous child abuse, domestic abuse.
- Opportunistic intervention by reactive agencies e.g. social care, police, reiterating key messages, ensuring messages are passed to caregivers.
- Crying baby is already an established problem e.g. health visitors, GPs, A/E staff.
- Need for out of hours advice: eg 111, parentline.
- Volunteer/Charity based parenting programmes, Peer support from volunteers, parent groups.
- Male caregivers/dads and mothers/female caregivers attending contact with babies.

### **6.3 Tertiary prevention: intervening when harm has occurred to prevent further harm and limit damage**

- Improved recognition and referral. Consideration of use of clinical rules to establish when to order investigations when the diagnosis is not clear.
- Child Advocacy Centre/Family Support centre provision.

### **6.4 Supportive prevention**

- Help for those families affected by AHT e.g. support groups, bereavement work.
- Education delivered by those families closing the loop in the prevention continuum.

### **6.5 Wrap around education:**

- All professionals, volunteers, parent groups/peer educators who have contact with families with babies to have access to accessible brief e-learning and materials.

### **6.6 Measuring Change options.**

- Impact on numbers of AHT victims – problematic in times of economic hardship as the incidence is likely to rise and it is not possible to say that it would have risen higher without the programme.
- Emergency Departments (EDs): Studies in Vancouver have shown a 25% reduction in the numbers of babies attending ED with ‘crying’. Given the current pressures on UK EDs this would be a sensible and easily achievable measure to replicate.
- Qualitative measures e.g. NSPCC: “Parents who have seen the film are more likely to react positively towards their baby’s crying and feel confident seeking help and support when needed”. Other qualitative measures include whether parents have remembered messages, have accessed the materials, have found them useful, have helped them cope. Caregivers could be approached to assess how much of the information has been shared with them by the parents.

### **6.7 Progress so far:**

Interest in the programme and requests for presentations have been shown by:

- NHS England NW Safeguarding Collaborative including all CCG safeguarding leads following a presentation in January.
- Manchester, Bury, Rochdale and Oldham Safeguarding Children Boards (presentations given at Manchester and Oldham. Presentations planned for Rochdale and Bury first week in March)
- Gloucester Safeguarding Children Board.
- West Hampshire CCG
- University of Birmingham.
- Charlees Angels Charitable Foundation and Support Group for families affected by AHT.

## 7. Conclusions:

The aim of this Fellowship was to explore international programmes related to the prevention of child maltreatment with a particular focus on AHT in infants and to gain an understanding about the wider context of the delivery of care and the systems and processes in which they are provided and commissioned.

Although access to health and social care is markedly different across USA and Canada compared to the UK, the challenges of service delivery, the demands on the systems and the changing face of health of different populations are very similar. This makes the transferability of my findings and emerging proposals achievable and tangible and have added authority and evidence to my intended outputs. The experience and learning gained has provided me with the inspiration and ideas to take forward my intended outputs.

- Establishment of a multiagency/multi disciplinary working party the terms of reference of which will include enhancing assessment and intervention of parenting capacity and coping ability in relation to excessive crying in infancy within health, education and social care delivery. The group will include parents: all the presentations I have delivered thus far have resulted in support of this as a way forward. As soon as I have received full endorsement from the Local Safeguarding Children's Boards (LSCB), the development of this group will begin alongside the events for parents and families affected by AHT.
- Development of a suite of prevention programmes aligned with public health levels of prevention: a broad outline has been agreed and upon LSCB endorsement, the parents and families' and professionals' groups can begin to recommend materials.
- Pilot programmes within selected acute and community health environments: This is likely to be across Rochdale and Oldham footprint of my employing Trust as there have been a number of Serious Case Reviews relating to AHT over the last 4 years in those areas. The LSCBs have shown a great deal of interest and agree the proposal outline.

The rest of the proposal will depend on the completion of the above and on the work with University of Birmingham who are meeting to discuss funding bids and research design in March.

- Complete impact evaluation of pilot including feedback from parents and professionals.
- Finalise programme and present to Clinical Commissioning Groups and Local Safeguarding Children Boards.
- Secure resource for integration of programmes into mainstream services.
- Apply for research grant capture bids for research study.
- Disseminate findings.

In conclusion, the incidence of AHT in babies in the UK is not going down. Despite the catastrophic and often fatal outcomes associated with this form of abuse, there is no co-ordinated campaign locally, regionally or nationally. More can be done in the UK to prevent AHT. A coordinated prevention programme that fits into the levels of public health prevention and which provides touchpoints of delivery across the multi agency health and social care economy could be incorporated into existing service delivery models in the UK. The proposed model described at 5.1 onwards spreads the delivery and responsibility across all agencies without imposing a single onerous intervention on one area and is based on four simple but crucial messages:

- Infant crying is normal and it will stop.
- There are comfort methods you can use that will sometimes sooth the baby and the crying will stop.
- Sometimes the soothing methods won't work and the crying can get to you. If this happens check your baby is safe - then walk away.
- Never ever shake or hurt a baby.

The detail of the proposed AHT prevention campaign will be co- designed by parents, families and professionals and experts in the field and underpinned by substantial evidence, and possibly materials, derived from the evaluation of the foundation programmes that are well established in the USA and Canada.

The ultimate aim is that the four point message and the programme that embodies it, become so embedded in the consciousness of professionals and public that more parents learn to cope with crying and more babies are protected from this preventable and catastrophic form of child abuse.

## **8. Recommendations:**

- Gain endorsement and support from LSCBs, Children's Trusts/Partnerships, Health and Well-being Boards and CCGs and NHS England.
- Identify champions from each agency and within key stakeholder organisations.
- Establish a multi agency steering group including parents/carers to co-design the detail of the campaign.
- Consider purchase of the Period of Purple Crying package to 'lift and shift' to UK:
  - Hold focus group of parents to test products.
  - Cost programme purchase.
  - Seek funding.
- Consider alternative of producing materials.
  - Hold design workshop with parents and professionals
  - Cost programme creation
  - Seek funding.

- Work with interested Universities to develop research protocol/evaluation design and bid for grant funding.
- Produce strategic plan including evaluation strategy and cost benefits analysis.
- Complete stage one action plan as below.
- Submit abstracts for conferences.
- Publish papers in selected relevant journals : e.g. International Journal of Birth and Parent Education.

***Draft Action Plan for Phase One:***

Action	Timescale
<b>Phase 1: Primary: Hospital, post natal, HV and public awareness raising element PLUS Secondary: reactive agencies message reinforcement element.</b>	
Hold events with parents/carers to consult on materials and programme content.	April 30th 2017
Hold events with identified group of families affected by AHT to consult on materials and programme content.	April 30th 2017
Hold events with professionals to consult on materials and programme content.	April 30th 2017
Establish a multi agency steering group including parents/carers to co-design the detail of the campaign.	April 30 <sup>th</sup> 2017
Establish University support and evaluation plan	April 30 <sup>th</sup> 2017
Consolidate funding sources (charitable/LSCB/Innovation project funding).	May 2017
Design and produce and/or purchase draft materials.	June 2017
Advance notice for stakeholder launch	August 2017

event.	
Produce progress report for stakeholders.	September 2017
Start discussions re: design and implementation of Phase 2.	September 2017
Prepare press release material for stakeholder launch events and 'Go Live' event.	September 2017
Finalise evaluation strategy with involved universities and collate baseline evaluation data	September 2017
Sign off materials from parents, families and professionals groups and agree launch date.	October 2017
Produce training materials for professionals.	October 2017
Hold stakeholder launch events at each pilot site.	November 2017
Undertake training for professionals/volunteers.	November, December, January.
Phase 1: Pilot Go Live Date	February 2018.
Complete pilot evaluation	July 2018
Amend/refine programme as per evaluation recommendations.	August 2018
Phase 1 Go Live	September 2018

## 9. References:

Atlman RL., Canter J., Patrick PA., Daley N., Neelofar K., (2011) Parent Education by Maternity Nurses and Prevention of Abusive Head Trauma *Pediatrics*: 128;e1164

Baildam E.M., Hillier V.F., Ward B. S., Bannister R.P., Bamford F.N., Moore W.M. (1995) Duration and pattern of crying in the first year of life. *Developmental Medicine and Child Neurology* 37, 345-353

Barlow KM., Minn RA., (2000) Annual Incidence of Shaken impact syndrome in young children *Lancet* 356: 1571 – 2.

Barr R.G., Hopkins B., Green J.A. (2000) *Crying as a sign, a symptom and a signal: clinical, emotional and developmental aspects of infant and toddler crying* London: MacKeith Press

Barr R.G., Trent R. B., Cross J., (2006) Age related incidence curve of hospitalized shaken baby syndrome cases: convergent evidence for crying as a trigger to shaking. *Child Abuse & Neglect* 30(1) 7-16

Barr R G, Rajabali F, Aragon M; Colbourne M., Brant R. (2015) Education About Crying in Normal Infants Is Associated with a Reduction in Pediatric Emergency Room Visits for Crying Complaints *J Dev Behav Pediatr* 36:252–257,

Barr R.G, (2012) Preventing abusive head trauma resulting from a failure of normal interaction between infants and their caregivers *Proceedings of the National Academy of Sciences of the USA* 109:2 p17297-17301

Belsky J, (1984) The determinants of parenting: a process model *Child Development* 55, 83-96

Berger RP., Fromkin JB., Stutz H., Makoroff K., Scribano PV., Feldman K., Chuan Tu L., Fabio A. *Pediatrics* DOI: 10.1542/peds.2010-2185

Bronfenbrenner U (1979) *The Ecology of Human Development* Cambridge, MA; Harvard University

Denise Coster D., Bryson C and Purdon S (2015) *Evaluation of Coping with Crying: Final Report* NSPCC

Dakof G.A., Taylor S.E., (1990) Victims perceptions of social support: what is helpful from whom? *Journal of Personality and Social Psychology* 58: 80-89

Department of Health (DoH) (1995) *Child Protection: Messages From Research* HMSO

Department of Health (DoH) (1995) *Child Protection: Messages From Research* HMSO

Department of Health (DH) (2009) The Healthy Child Programme: Pregnancy and the first five years of life COI for DH.

Dias et al (2005) Preventing Abusive Head Trauma Infants and Young Children: a hospital based prevention program Pediatrics 115: 470 – 477

Dubowitz H., Feigleman S., Lane W., Kim J., (2009) Pediatric Primary Care to Help Prevent Child Maltreatment The Safe Environment for Every Kid (SEEK) model Pediatrics 123:3

Feigelman S, Dubowitz H, Lane W, Grube L, Kim J (2011) Training Pediatric Residents in a Primary Care Clinic to Help Address Psychosocial Problems and Prevent Child Maltreatment. Academic Pediatrics. 11(6):474-80.

Folkman S., (1992) Making the case for coping IN Carpenter B.N. (ed) Personal Coping: theory research and application Praeger: New York p. 31-46

Geen R.G. (1990) Human Aggression Milton Keynes: Open University Press

Iwaniec, D (2006) The Emotionally Abused and Neglected Child: Identification, Assessment and Intervention (2<sup>nd</sup> Ed) Wiley & Sons: London

Jenny et al 1999, Analysis of missed cases of abusive head trauma JAMA 281: 621-626

Kemp A., (2011) Abusive Head Trauma: Recognition and the essential investigation Archives of Diseases in Childhood Edu Pract Ed 96, 202 – 208

Kesler, H., Dias, M., Schaffer M., Rottmund C.k, Cappos K., Thomas NJ. (2008) Demographics of Abusive Head Trauma in the Commonwealth of Pennsylvania Journal of Neurosurgery: Pediatrics 1 (5) 351-356

Long T and Johnson M (2001) Living and Coping with Excessive Infantile Crying Journal of Advanced Nursing 34(2), 155-162

Miller S., Sambell K., (2003) What do Parents feel they need? Implications of parents perspectives for the facilitation of parenting programmes Children and Society 17: 32-44

Moran P., Ghate D., Van der Merwe A., (2004) What Works in Parenting Support? A review of the International Evidence Policy Research Bureau: DfES

Redman S., Taylor J., (2006) Legitimate Family Violence as represented in the print media: textual analysis Journal of Advanced Nursing 56 (2), 157-165

Reijneveld S.A., Van der Wal M.F., Brugman E.M., Hira Sing R.A., Verloove-Vanhorrick S.P., (2004) Infant crying and abuse The Lancet 364:1340-42

Showers J (1992) “Don’t Shake the Baby”: the effectiveness of a prevention program Child Abuse & Neglect 16: 11-8

St. James-Roberts I., Hurry J., Bowyer J. (1993) Objective confirmation of crying duration in infants referred for excessive crying. Archives of Disease in Childhood 68, 82-84

Straus M.A., (1980) Sociological Perspective on the Causes of Family Violence 1980 IN Geen M.R. Violence and the Family Washington American Assoc for the Advancement of Science DC

Wade K., Black A., Ward-Smith P., (2005) How mothers respond to their crying infant Journal of Pediatric Health Care 19: 347-353

Watkins D., Cousins, J., (2005) Child Physical Punishment, Injury and Abuse (part 2) Community Practitioner 78 (9), 318-321

## 10. APPENDICES

### APPENDIX ONE

#### ITINERARY PHASE ONE.

Date	Time	Location	Address	Contact	Activity
<b>Sun 4/9/2016</b>	21.11	Arrive Baltimore Airport	Holiday Inn, Washington College Park.		
<b>Monday 5/9/2016</b>	All day	Baltimore		Howard Dubowitz	Visit the area, confirm times and dates, arrange travel.
<b>Wed 7/9/2016</b>	All day	University of Maryland Medical Centre	Baltimore	Howard Dubowitz	<ul style="list-style-type: none"> <li>• Meet HD, discuss SEEK programme</li> <li>• Attend Grand Round Lecture</li> <li>• Meet with medical student</li> </ul>
<b>Thurs 8/9/2016</b>	AM	Paediatric Clinic	Midtown, Baltimore	Sue Fiegleman	<ul style="list-style-type: none"> <li>• Observe SEEK in practice</li> <li>• Discuss delivery of primary health care and role of paediatrician.</li> </ul>
<b>Friday 9/9/2016</b>	AM	University of Maryland Children's Hospital (UMCH)	Baltimore	Connie Grossart	<ul style="list-style-type: none"> <li>• Meet Director of Nurse Practitioners and Physician Assistants, Carmel McComiskey and Director of Patient Experience and Commitment to Excellence, Kerry Sobol.</li> <li>• Meet Shannon Joslin, Child Life Manager.</li> <li>• Tour of area with Connie.</li> </ul>
<b>Saturday 10/9/2016</b>	All Day		Hotel		Write up and pack
<b>Sunday 11/9/2016</b>	9.15	Depart Baltimore Airport			
<b>Sun, 11/9/16</b>	Arrival 12:14 PM	Harrisburg International Airport (HIA)	Harrisburg/ Middletown	Mark & Anita Dias	American Airlines AA4823 Phila to Hbg

<b>Mon, 12/9/16</b>	All Day	TBD	TBD	Mark & Anita Dias	Visit the area with Anita
<b>Tues, 13/9/16</b>	9 AM-10 AM	Penn State Hershey Medical Center Room C7842	Hershey	Lori Frasier, Kate Crowell, Kent Hymel, & Heather Hoffman	Center for the Protection of Children Case Review meeting & possibly meet with CPC director
	10 AM-12 PM	Penn State Hershey Medical Center, Centre for Child Protection	Hershey	Kent Hymel	Meet with Child Abuse Pediatricians
	12-5 PM	Lancaster County	Lancaster	Anita Dias, Carroll Rottmund, & Kelly Cappos	Meet with Carroll in Lancaster re: child death review, death scene investigation then tour Lancaster Amish Country
<b>Wed, 14/9/16</b>	10-11 AM	Penn State Hershey Medical Center Lobby	Hershey	Michael Ringenbach	Tour of Children's and Main Hospital; end at the NICU
	11- 11:20 AM	Penn State Hershey Medical Center NICU	Hershey	Jill Arnold	Meet with NICU manager
	11:30-12 PM	Penn State Hershey Medical Center Women's Health	Hershey	Ann Marie Trovato	Tour of Women's Health Unit & meet with staff nurse
	1-2 PM	Penn State Hershey Medical Center Room P4205	Hershey	Michelle Smith	Presentation to PICU nurses
	2:15-3:30 PM	Granada Room 2106	Hershey	Kelly Cappos	Visit the PA Prevention Program office
<b>Thurs, 15/9/16</b>	9-10 AM	Pinnacle Health Harrisburg Hospital	Harrisburg	Kate Bilger	Meet in lobby for hospital tour by Kate and meeting with OB management team

	10:30-11:30 AM	Holy Spirit Hospital	Camp Hill	Marie Carr, Enid Kreiner, & Darlene Heiges	Meet in lobby for hospital tour by Darlene and meeting with OB management team
	1:30-2:30 PM	Children's Resource Center	Harrisburg	Lynn Carson	Tour of the CRC and meet with Lynn
	3:00-3:30 PM	Highmark Caring Place	Lemoyne	Terri Bowling	Tour of the Highmark Caring Place
<b>Fri, 16/9//16</b>	9:30 AM-12 PM	Penn State Hershey Medical Center	Hershey	Mark Dias	Lunch discussion about AHT prevention in NY & PA
<b>Sat, 17/9//16</b>	Down Time			Mark & Anita Dias	
<b>Sun 18/9/2016</b>	11.00	Depart Harrisburg Airport			Delayed
<b>Monday 19/9/2016</b>	01.30	Arrive Buffalo Airport			
<b>Tues 20/9/2016</b>	12.30	Buffalo Women and Children's Hospital	Buffalo	Kathy deGuehery	<ul style="list-style-type: none"> <li>• Discussion about programme</li> <li>• Look at materials</li> <li>• Visit to Niagara Falls</li> </ul>
<b>Weds 21/9/2016</b>	12.30	Buffalo Women and Children's Hospital	Buffalo	Kathy deGuehery	<ul style="list-style-type: none"> <li>• Visit NICU</li> <li>• Visit Maternity wards</li> <li>• Tour of area</li> </ul>
<b>Thur 22/9/2016</b>	13.00	University of Buffalo	Buffalo	Kathy deGuehery	<ul style="list-style-type: none"> <li>• Visit Director of Nurse Education.</li> </ul>
<b>Fri 23/9/2016</b>	All Day	Hotel	Buffalo		Write up and pack
<b>Sat 24/9/2016</b>	10.45	Depart Buffalo Airport			
	17.02	Arrive Montreal Pierre Elliott Trudeau Airport			
<b>25 – 27/9/2016</b>	All Day	National Center of Shaken Baby Syndrome International Shaken Baby Conference	Montreal		Programme of events
<b>28-29/9/2016</b>	08.20	Arrive Home			

## ITINERARY PHASE TWO

<b>Date</b>	<b>Time</b>	<b>Location</b>	<b>Address</b>	<b>Contact</b>	<b>Activity</b>
<b>Sunday 30/10/2016</b>	20.00	Arrive in Vancouver	Coast Vancouver Airport Hotel		
<b>Monday 31/10/2016</b>	All Day	Vancouver		Claire Humphreys	Visit the area, Confirm times/dates, arrange travel.
<b>Tues 1/11/2016</b>	12.30	Vancouver	BC Children's Hospital	Mrs Marilyn Barr and Dr Ronald Barr	<ul style="list-style-type: none"> <li>Lunch and discussion re: origins of PURPLE and underpinning research</li> </ul>
<b>Weds 2/11/2016</b>	10.00	Vancouver	BC Children's Hospital	Claire Humphreys	<ul style="list-style-type: none"> <li>PURPLE products, development, watch videos.</li> </ul>
	12.00	Vancouver	BC Children's Hospital	Claire Humphreys	<ul style="list-style-type: none"> <li>Presentation for BC Children's Hospital Research Group.</li> </ul>
<b>Thursday 3/11/2016</b>	13.30	Vancouver	BC Women's Hospital	Gail Brito, programme coordinator at BC Women's Hospital	<ul style="list-style-type: none"> <li>Discuss delivery of PURPLE at maternity level.</li> </ul>
	15.30	Vancouver	BC Children's Hospital	Fahra Rajabali Research assistant.	<ul style="list-style-type: none"> <li>Learn about measures of success including recent study re: impact on ED attendances.</li> </ul>
<b>Friday 4/11/2016</b>	All Day	Vancouver			<ul style="list-style-type: none"> <li>Write up, pack, site seeing (Stanley Park)</li> </ul>
<b>Sat 5/11/2016</b>	12.45	Vancouver Airport			Depart for Montana.
	21.04	Arrive Helena Airport			
<b>Sun 6/11/2016</b>	All day				Visit area, confirm times/dates, arrange transport

<b>Mon 7/11/2016</b>					Sight seeing
<b>Tuesday 8/11/2016</b>	12.30	Helena	Lewis and Clarke Child Advocacy Centre	Paula Samms	<ul style="list-style-type: none"> <li>Learn about the function of CACs, funding, leadership.</li> </ul>
<b>Wed 9/11/2016</b>	11.00	Helena	Healthy Mothers Healthy Babies	Sarah Corbally	<ul style="list-style-type: none"> <li>Discussion about the challenges of funding and delivering PURPLE and impact of political changes.</li> </ul>
<b>Thur 10/11/2016</b>	Afternoon	Helena		Jen Shaw	<ul style="list-style-type: none"> <li>Previous project lead of PURPLE. Discussions re: measuring change and showing impact. Challenge of measuring prevention in short timescale.</li> </ul>
<b>Fri 11/11/2016</b>	Afternoon	Helena		Jen Shaw	<ul style="list-style-type: none"> <li>Tour of the area. Further discussions.</li> <li></li> </ul>
<b>Sat 12/11/2016</b>	All day				<ul style="list-style-type: none"> <li>Write up, pack, sight seeing.</li> </ul>
<b>Sun 13/11/2016</b>	07.15	Helena Airport			Depart Helena, Montana
	12.17	Wichita Airport			Arrive in Wichita
<b>Monday 14/11/2016</b>	All Day	Wichita	Wichita Inn Airport, West Kellogg		Visit area, confirm times/dates, arrange transport
<b>Tuesday 15/11/2016</b>	10.00	Wichita	Kansas Children's Services League	Rachelle Rake	<ul style="list-style-type: none"> <li>Meeting with Vicky Roper, Director of Prevent Child Abuse Kansas at KCSL to discuss KCSL programme and implementation of PURPLE. Tour of KCSL</li> </ul>
	11.30	Wichita	Kansas Children's Services League	Rachelle Rake	<ul style="list-style-type: none"> <li>Meeting with Rachelle Rake to discuss PURPLE in detail</li> </ul>
	14.00	Wichita	Wesley Hospital	Rachelle Rake	<ul style="list-style-type: none"> <li>Meet with Cyndy Chapman to discuss PURPLE implementation at Wesley (largest implemented hospital in KS).</li> </ul>
<b>Weds 16/11/2016</b>	10.00	Wichita	Kansas Children's	Rachelle Rake	<ul style="list-style-type: none"> <li>Dose 3. Click for Babies campaign logistics.</li> </ul>

			Services League		
	12.00	Wichita	Kansas Children's Services League	Rachelle Rake	<ul style="list-style-type: none"> <li>• Mandatory Child Abuse Reporting training.</li> </ul>
	16.00	Wichita		Rachelle Rake	<ul style="list-style-type: none"> <li>• Tour of area</li> </ul>
<b>Thur 17/11/2016</b>	11.00	Wichita	Kansas Children's Services League	BJ Gore	<ul style="list-style-type: none"> <li>• Meeting to discuss reaching men in prevention programmes.</li> </ul>
	13.00	Wichita	KIDS Safe Sleep	Christy Schunn	<ul style="list-style-type: none"> <li>• Meeting to discuss the delivery of the safe sleep message and how it can be integrated with AHT.</li> </ul>
<b>Fri 18/11/2016</b>	All Day	Wichita			<ul style="list-style-type: none"> <li>• Write up, pack, sight seeing</li> </ul>
<b>Sat 19/11/2016</b>	12.19	Wichita Airport			<ul style="list-style-type: none"> <li>• Depart Wichita to fly back to Manchester.</li> </ul>



## Parent Questionnaire (PQ)

**Dear Parent or Caregiver:** Being a parent is not always easy. We want to help families have a safe environment for kids. So, we're asking everyone these questions. They are about problems that affect many families. If there's a problem, we'll try to help.

Please answer the questions about your child being seen today. If there's more than one child, please answer "yes" if it applies to any one of them. This is voluntary. You don't have to answer any question you prefer not to.

Today's Date: \_\_\_/\_\_\_/\_\_\_                      Child's Name:

\_\_\_\_\_  
 Child's Date of Birth: \_\_\_/\_\_\_/\_\_\_                      Relationship to Child:

### PLEASE CHECK

- Yes     No    Do you need the phone number for Poison Control?
- Yes     No    Do you need a smoke detector for your home?
- Yes     No    Does anyone smoke tobacco at home?
- Yes     No    In the last year, did you worry that your food would run out before you got money or Food Stamps to buy more?
- Yes     No    In the last year, did the food you bought just not last and you didn't have money to get more?
- Yes     No    Do you often feel your child is difficult to take care of?
- Yes     No    Do you sometimes find you need to hit/spank your child?
- Yes     No    Do you wish you had more help with your child?
- Yes     No    Do you often feel under extreme stress?
- Yes     No    In the past month, have you often felt down, depressed, or hopeless?

Appendix Three

**PLEASE PRESS HARD WHEN COMPLETING THIS FORM, YOU ARE MAKING 3 COPIES.**



**Pennsylvania Shaken Baby Syndrome Prevention Program**  
*"Saving babies' lives one family at a time."*

**VOLUNTARY COMMITMENT STATEMENT**  
**(DECLARACIÓN DE COMPROMISO VOLUNTARIO)**

**Hospital/Birth Center Instructions:** Complete one form for each infant. Provide parent(s) with information about shaken baby syndrome and prevention measures. Request that they voluntarily sign this form indicating that they have received and understand the information. Provide the parents with one copy of this signed form, retain one copy in the medical record, and forward one copy to the Nurse Coordinators of the Pennsylvania Shaken Baby Syndrome Prevention Program.

**Instrucciones para el Hospital/Centro de Parto:** Llene un formulario por cada infante. Entregue al padre / madre o ambos información sobre el síndrome del bebé sacudido y su prevención, y pídale que firmen este formulario voluntariamente indicando que han recibido y comprendido la información. Entrégueles una copia del formulario firmado y archive otra en el hospital / centro de parto, y entregue una copia a los coordinadores de enfermería del Programa de prevención del síndrome del bebé sacudido de Pennsylvania (Pennsylvania Shaken Baby Syndrome Prevention Program).

**HOSPITAL NAME:** \_\_\_\_\_  
*(NOMBRE DEL HOSPITAL)*

**BABY'S LEGAL NAME:** \_\_\_\_\_  
*(NOMBRE LEGAL DEL BEBÉ)*

**DATE OF BIRTH:** \_\_\_\_\_ **SEX:** M  F   
*(FECHA DE NACIMIENTO) (MM/DD/YY) (MM/DD/AA) (SEXO)*

**PARENT(S) PROVIDED SHAKEN BABY SYNDROME INFORMATION, DATE:** \_\_\_\_\_  
*(EL PADRE O LOS PADRES RECIBIERON LA INFORMACIÓN (MM/DD/YY) (MM/DD/AA) SOBRE EL SÍNDROME DEL BEBÉ SACUDIDO, FECHA)*

Discussed with Nurse  Viewed Video  Received Brochure  
*(Habló con el personal de enfermería) (Vio el Video) (Recibió el folleto)*

**NOTES:**  
**NOTAS:**

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**Parent:** Information about Shaken Baby Syndrome has been presented to me by the hospital. I voluntarily sign this statement acknowledging that I have received, read and understand this information.  
*(Padre/Madre: He recibido la información sobre el Síndrome del Bebé Sacudido, y voluntariamente firmé esta declaración reconociendo que he recibido, leído y comprendido la información)*

**SIGNATURE, MOTHER:** \_\_\_\_\_  
*(FIRMA, MADRE)*

**SIGNATURE, FATHER:** \_\_\_\_\_  
*(FIRMA, PADRE)*

**SIGNATURE, OTHER:** \_\_\_\_\_  
*(FIRMA, OTRO)*  
(stepparent, adoptive parent, legal guardian, legal custodian)  
 (padrastro, madrastra, padre adoptivo, tutor legal, custodia legal)

**REFUSED:**  **DATE:** \_\_\_\_\_  
*NO ACEPTÓ (FECHA)*

**REFUSED:**  **DATE:** \_\_\_\_\_  
*NO ACEPTÓ (FECHA)*

**REFUSED:**  **DATE:** \_\_\_\_\_  
*NO ACEPTÓ (FECHA)*

This form and accompanying information provided in compliance with Act 176 of 2002 (11 P.S. §2121-2126).  
*Este formulario y la información que le acompaña se entregaron en conformidad con la Ley 176 de 2002 (11 P.S. §2121-2126).*

(5/13)



# Prevention Strategy Matrix

PRIMARY (Universal) Prevention Strategy	SECONDARY (Targeted) Prevention Strategy	TERTIARY (Selected) Prevention Strategy
Parent Helpline	Head Start	Adoption Search
Community Resource Library (includes parent tip cards)	Early Head Start Kansas Early Head Start	Adopt Kansas Kids/Klicks for Kids & Kansas Post Adoption Resource Center
Period of PURPLE Crying (shaken baby syndrome education)	Healthy Families America Home Visitation	From Heart to Home Infant Adoption
Governor's Conference on the Prevention of Child Abuse & Neglect	Parents Helping Parents Support Groups	Compass Resource Families & TIPS-MAPP (foster parent) Training
e-Learning Training Opportunities (human service professionals)	Parent Training	Healthy Relationship Retreats
Child Abuse Prevention Month Activities	Fatherhood Groups	Drug Endangered Child Case Management
Parent Leadership Conference	Supporting School Success Case Management	Center for Restorative Education
Child Abuse and Neglect Prevention Trainings	Outpatient Mental Health	OASIS Runaway Youth Case Management
Darkness to Light Trainings (child sexual abuse prevention)	Crisis Nursery Case Management	Juvenile Intake Assessment
Fatherhood	Kinship Navigation	
Wichita Coalition for Child Abuse Prevention		

■ Statewide 
 ■ Multiple KCSL Regions 
 ■ West Region Only 
 ■ Wichita Only 
 ■ Topeka Only

**BRIEF DEFINITION OF STRATEGY TYPE:**

- Universal** - All parents and caregivers can benefit from the service or information
- Targeted** - Services and supports focused on increasing the protective skills of at-risk groups of parents/children
- Selected** - Service intervention designed to prevent abuse/neglect from happening again



**Winston Churchill Memorial Trust Fellow Studies AHT  
Prevention in the United States and Canada**

It was our absolute pleasure to host Suzanne Smith, PhD from the United Kingdom for one week this past September. Dr. Smith was the recipient of the prestigious Winston Churchill Memorial Trust Travel Fellowship. According to their website <http://www.wcmt.org.uk/> their motto is *“Travel to learn – return to inspire...we fund British citizens to investigate inspiring practice in other countries, and return with innovative ideas for the benefit of people across the United Kingdom.”*

Sue has a passion for protecting infants and children from abuse thus she selected the study of infant abusive head trauma prevention in North American and Canada as her educational focus. She spent one week each in Baltimore, Maryland; Hershey, Pennsylvania; Buffalo, New York; Montreal, Quebec Canada; Vancouver British Columbia, Canada; Helena, Montana and will complete her studies in Wichita, Kansas, before heading home. It was fascinating to discuss the healthcare system in the UK with Sue and learn about their implementation of universal home visitation to support mothers and babies after birth.

We wish to thank everyone who helped to make Dr. Smith’s time in Pennsylvania such a positive experience especially: Dr. Lori Frasier, Dr. Kate Crowell, Dr. Kent Hymel, & Heather Hoffman (Penn State Hershey Center for the Protection of Children/Children’s Hospital); Michael Ringenbach (Four Diamonds); Carroll Rottmund (Lancaster County Coroner); Vic Zittle (Child Death Review); Ann Marie Trovato & Julie Becker (Penn State Hershey Women’s Health), Kate Bilger, Deb Shaeffer, Marianne Allen, Tina Willier, and Jena Hagey (Harrisburg Hospital); Enid Kreiner & Darlene Heiges (Holy Spirit Hospital); Lynn Carson (Children’s Resource Center), and Terri Bowling (The Highmark Caring Place). Each of you were an important piece of the total picture for Sue to understand the prevention efforts and resources available for children in Pennsylvania.

*“The prevention of Abusive Head Trauma has been a passion of mine since I saw, first hand in the 1990s, the devastation that it causes. Traveling to PA to meet Dr. Mark, & Anita Dias, was a huge honour for me as I had read so much of Dr. Dias’ wonderful work. Seeing his programme in Hershey and in Buffalo, how it has developed and grown and the energizing dedication of his team has been inspirational to me. During my visit, I also wanted to understand more about the United States healthcare system and culture. PA Nurse Coordinator Kelly Cappos certainly made this happen for me and introduced me to some wonderful professionals with obvious passion for their work both in the hospitals, in the community and in forensic services. I re-connect with those experiences everyday, thinking how I could take them forward in my own workplace. Apart from the work side of things, I was so fortunate to meet such warm and friendly people and visit some awe-inspiring places. Thanks to this unique opportunity afforded to me by the Winston Churchill Memorial Trust Travel Fellowship, the threads of the different programmes I have learned about are forming the framework for my work at home and I have a lot of interest from colleagues in the UK about what will emerge from my work when it has finished. The most important part of this experience for me is that I have met people who I know will be my friends forever.”*



**Dr Suzanne Smith PhD, MA, RGN, RHV, BA**  
Assistant Director of Nursing  
The Pennine Acute Hospitals NHS Trust  
North Manchester General Hospital  
Delauney’s Rd, Crumpsall, Manchester M8 5RB  
tel: 0161 918 4698 (Int 44698) Mobile: 07973 913629  
email: [suzanne.smith@pat.nhs.uk](mailto:suzanne.smith@pat.nhs.uk) web: [www.pat.nhs.uk](http://www.pat.nhs.uk)

*A heartfelt “Thank You” to everyone who warmly welcomed Dr. Suzanne Smith. You were a special part of her once in a lifetime experience!*

