Does it Take a Village? How Do We Support the Vulnerable Families of Vulnerable Babies?

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Introduction

The incidence of premature birth and birth complications is not random. Lower social class, poorer education, single marital status, low income, trouble with “nerves” and depression, help from professional agencies, and little contact with neighbours are all significantly associated with an increased risk of preterm birth (Peacock et al., 1995; Wadhwa et al., 2001). Later outcomes show that the social determinants of health operate across and even within relatively affluent societies, adding to or mitigating initial risks. Following premature birth there is an association between gestational age and cognitive development but socio-economic indicators modify this effect (Ekeus et al., 2010). As well as the direct risks of prematurity, there is an additional burden on the least favoured in society resulting in poor physical and emotional wellbeing as well as life expectancy (Wilkinson & Marmot, 2003).

Keeping vulnerable babies alive and physically well is a necessary but not sufficient guarantee of their later wellbeing and positive emotional as well as physical health. Much of the variation in outcome will depend on the quality of environment they meet after delivery and the strongest proximal indicator is the quality of the emotional relationships they make. These relationships and the attachment patterns they form have a critical effect on all aspects of their later life (Phillips & Shonkoff, 2000; Shonkoff and Fisher, 2013). If the environment which the baby meets is emotionally and developmentally barren then his or her outcome will be commensurately worse. Parents who are themselves vulnerable may be in a less good position to provide the responsive care and stimulation the baby needs particularly when their own experiences of loving care are lacking. Understanding and responding to the needs of parents may help to prevent the double disadvantage conveyed by premature birth compounded by social and economic adversity. All parents need support but those with additional needs may need “a village” and long term support to enable them to parent well, and respond to the changing needs of a developing child. This paper will describe the experiences of one family, with a child born prematurely, and how services responded to their needs, beyond the neonatal period.

Case history

In November 2010 a 32 week baby, Kieron1, was delivered by emergency C-section, to an 18 year old mother and her 21 year old partner. There had already been a pre-birth case conference (equivalent to child protection case conference) due to anxiety about Karen’s ability to care for a child. Her mother had recently died and her 1 year old sister was taken into care and subsequently adopted away. Karen had also recently had a “falling out” with her partner David and so lacked support. Karen and David had no diagnoses of intellectual deficits but both struggled with literacy.

When she collapsed, vomiting, at a bus stop a week after her waters had broken, Karen was taken to the maternity unit and it was quickly decided that a C-section was needed. After delivery, Kieron had difficulty breathing so his father was not allowed to cut the cord as they had planned, and the parents did not have the chance to hold him. Kieron was in and out of NICU for more than 2 weeks, needing CPAP to assist his breathing. A cannula was wrongly inserted, and the resultant infection led to complications and eventual plastic surgery to repair the scars. At 3 weeks, Kieron was discharged to foster care with Karen and David having regular contact with him.

Karen described the experience of having her child removed:
“ Weird for me as a mum. I never had a chance to understand Kieron nor Kieron to understand me. We never had that bond”.

David said he felt sad that his first son did not go home with him.

1 Parents have given signed consent to discussion of their family, and quotes are taken from a recent interview with them. All names have been changed to protect their anonymity.
Parents' background
Karen's mother had learning difficulties and had difficulty in parenting Karen. As a result Karen was reared largely by her grandmother and lost a lot of schooling. She was bullied at school and still has some psychological difficulties. She still has difficulties with literacy.

David was reared by his single mother after his parents split up when he was about 10 years old. He had 2 brothers and a sister but his mother never had time for any of them. If he approached his mother she simply told him to "go away". David speaks less than Karen and is often difficult to understand. If asked direct questions he often seems lost for an answer.

Karen and David had a somewhat rocky relationship. They sometimes drank a little too much or took soft drugs, and there was some fighting between them. David denies anger problems as such, but feels that he will act before he thinks.

The rest of the story
When Kieron was coming up to a year old, he was returned to the care of his parents. Karen said: "We were handed a black bag of clothes and a baby we did not know to take home".

The family then received a welter of services, from social work, home support and day care, health visitor, paediatrician, a child psychologist, housing support and supported living services. Kieron was given a nursery placement. Each of these services visited or made appointments at different times with Karen and David running to keep up with the sometimes conflicting demands. When Kieron hit his head and was taken to A&E, this was recorded as a non-accidental injury and David was forbidden to be in sole charge of him. Social workers sent the police to Kieron's nursery and took David away, in front of other parents who then asked if he was a danger to their children too.

Karen described feeling overwhelmed by the services, and subject to impossible demands.

When Kieron was vomiting during the night she rang the nursery to ask whether she should give him something to eat next morning or not. Within a short time, the health visitor, social worker and home support and day care staff were all at her door and she felt that rather than the help she understandably requested she was "investigated", with services conspiring to "go behind [her] back". She was told "we are here to help" but felt "we could not trust them". The demands on David and Karen do seem to have been out of proportion. If Karen was not at home by 5pm, she was criticised for failing to have a good routine for Kieron. On one occasion she asked the nursery if she could collect Kieron half an hour early one afternoon so he could attend a family party to celebrate her grandmother's 80th birthday. The nursery agreed this, but at the next case conference she was criticised for undermining Kieron's education. Karen had trouble keeping Kieron entertained on bus journeys and described giving in to his demands, buying him toys, feeding him crisps and letting him out of his buggy whereupon he jumped on the seats. When she asked for help, she was criticised for "not coping" but the offer of accompanying her on a bus journey to offer support and devise strategies was never fulfilled.

When Kieron was 3 years old, social work services demanded that Karen be available to review the care plan at a time when she needed to collect Kieron from nursery. When she explained the time constraints she was told she had to "wait on us [social work]". She became angry and asked why it had to be done at that moment, when it could have been done at any other time in the preceding year. She argued with the social worker who then told her to go and collect Kieron. When she brought him home he was immediately removed into care.

At this point Karen, David and Kieron were offered support under the Glasgow Infant Family team an NSPCC project modelled on the Tulane University Infancy project, integrating support for parents and children, working with each separately and together as needed and working closely with social workers and foster carers in addition. After almost a year, Kieron returned home, this time on a very different basis, with time and opportunities for Karen and David to learn about his routines and to learn from his foster carer what strategies had worked for her. Kieron too was prepared with a gradual transition from overnight visits on a planned and agreed schedule to a full return home.

Current status
Kieron is now living at home with his parents. At a recent visit he appeared well and happy and discussed easily that he liked nursery as he has friends there. At age 4, he comfortably sat between his parents whom he introduced as "mum and dad". In discussing ages and birthdays, he was eager to demonstrate his prowess in counting to 11, and fractions, as well as symmetry. His mother beamed with pleasure. He leant comfortably on his father and gave him a hug though he confided that his mum had said a "bad word" when she dropped
something earlier that day. Mum reminded him that this was a “bad word” and he should not repeat it and also not to interrupt when adults were talking. He was entirely compliant.

What helped and hindered?

Asked “What helped?”, Karen named having a routine, help from her gran and access to information. She particularly valued a chance to talk to other mums, in a Bounce and Rhyme group, based on Book Bug (www.scottishbooktrust.com/bookbug). She liked these sessions as they were not in a social work environment but a library, and gave her a chance to meet other mums and chat while they stayed for coffee, for example, about weaning foods and what worked for each of them. She found and attended this group on her own initiative but was then redirected by social work. They sent her instead to a Young Parent Unit in a high school where other much younger girls in their early teens were being helped to continue their education. She resented this as she felt she was too old at 18 and did not need further help with education.

David also said he would have liked guidance on how to recognise Kieron’s cues, for feeding or for play as well as later help with managing behaviour.

Discussion

It was a surprise to me to find that Karen, David and Kieron have suffered not from too few services but from too many un-coordinated interventions, perhaps not always the most appropriate, and delivered in ways that made them feel smothered and subject to sometimes competing demands with little respect for them as adults. It is clear that they needed help but they were well able to articulate the practical and information support they wanted. Too many services and impossible demands made them feel constantly scrutinised and their decisions disregarded. The principles of andragogy - that is, adult learning - include respecting adults and their own life experiences and knowledge. Adult learners are internally motivated and self-directed, they are goal-orientated and look for knowledge that is practical and relevant (Zmeyov, 1998; Fidishun, 2000; Russell, 2006). Bounce and Rhyme, where Karen found peer support and companionship, was brushed aside and she felt demeaned by being sent back to school where she felt out of place.

Of course, service providers are aware of previous serious case reviews where lack of joined-up services has been identified as a contributor to the death of a child (http://www.trixonline.co.uk/website/news/pdf/policy_briefing_No-99.pdf). Services tend to be risk-averse and perhaps at times heavy handed without due attention to the principles of andragogy and particularly respect for the parents as adults, the vast majority of whom do not wish their children ill though they may lack the knowledge and skills to offer the best environment. It would be simplistic and wrong to blame social workers who on the whole are working hard and with great dedication in a system that is broken. One attempt to address this dilemma has been the recent Children and Young People Bill in Scotland which allocated each child a named person who will act as a safeguarder for their wellbeing and health. The legislation has occasioned critical questioning of who these guardian angels will be and how they will be identified to the family and eventually to the child him/herself. Health visitors have traditionally had such a role but with caseloads into the hundreds at times, it is difficult to see how they can monitor and support so many children effectively on a personal knowledge basis.

Mellow Babies and Mellow Parenting

(www.mellowparenting.org)

Two programmes which have been devised particularly for vulnerable parents with under 1 year olds and under-5s respectively combine some helpful aspects of support for parents and babies. They meet the criteria defined by Bakermans-Kranenburg et al. (2003) as increasing parental sensitivity and improving parent-child attachment, including the use of video feedback to help mothers and fathers identify their own children’s cues and responses. As group programmes where parents share good ideas and problem-solve together, they could have met Karen’s seeking for peer support. Both programmes observe the principles of andragogy and have been shown to improve parental wellbeing as well as supporting good parent child interaction and enhanced child cognitive and language outcomes.

Conclusions

Vulnerable babies born into vulnerable families bear a double burden of adversity. It is understandable that in risk-averse practice, services can end up undermining and swamping parents. The introduction of a named person for each child in Scotland aims to mitigate that risk, but doubt has been cast on the practicalities of its effective implementation, which is due this year. Babies born prematurely need to be protected from the risk of too much, too little or the wrong sort of help compounding their birth problems. Systems that ensure that parents receive the right support at the right time, respect their wishes as far as possible, and include them as partners in their children’s welfare as part of the solution rather than the source
of the problem; will support vulnerable parents to protect vulnerable children. No one profession is the whole answer to the needs of families, but paediatric physiotherapists operate best as members of the multidisciplinary team.

References


