Supporting previously bereaved parents following the birth of a rainbow baby: a health visiting pilot

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Abstract

A ‘rainbow baby’ is the term used for a live child born after the parents have experienced a previous miscarriage, stillbirth or neonatal death. In the community, health visitors are well placed to provide support to bereaved families after the death of a child. However, recent NHS budgetary constraints mean that health visitors are often unable to provide the additional support that families require at such a challenging time or when they subsequently find that they are expecting another child. This article details a service evaluation of a health visiting pilot, which sought to provide parents with targeted support after the birth of a rainbow baby. The pilot provided a named health visitor to monitor the parents’ general mental health and provide trauma-informed parenting support. The author describes the background, development and evaluation of the pilot. Five sets of parents were surveyed and all stated that they found the pilot supportive and beneficial.

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Keywords

antenatal, babies, child health, clinical, fathers, health visitors, infants, mothers, neonatal, parents, public health, stillbirth

Why you should read this article:

- To learn more about health visiting bereavement support
- To understand how continuity is important following the loss of a baby
- To recognise how health visiting can support parents expecting a rainbow baby

HEALTH VISITORS are registered nurses and midwives who undertake additional training in community public health nursing. They provide a professional evidence-based public health service for individuals, families and communities with the aim of enhancing people’s health and reducing health inequalities (Institute of Health Visiting (IHV) 2024).

The author’s local health visiting service in Shropshire, England, adheres to the Healthy Child Programme, a national evidence-based programme for children aged 0-19 that seeks to promote health improvement, public health and support for families (Office for Health Improvement and Disparities 2023). The Healthy Child Programme is designed to support every family to make healthy choices in areas such as immunisation, using health information, developmental reviews and access to community services such as health visitor clinics (Office for Health Improvement and Disparities 2023). Reduced NHS budgets and low numbers of practising health visitors have made it challenging to deliver more than the core contacts mandated by the Healthy Child Programme and families often experience only minimal core contacts with health visitors (IHV 2022, Public Health England (PHE) 2021).

Following the birth of a child, families should receive an initial antenatal contact, visits at between ten and 14 days and six and eight weeks, then subsequent reviews at one- and two-year intervals (PHE 2016). The lack of public health funding is constraining the budgets of health visiting services (IHV 2020) so there is little opportunity for health visitors to offer families input over and above...
these mandated visits, including targeted visits following the death of a child.

The loss of a baby before, during or soon after birth continues to affect thousands of people across the UK every year (Office for National Statistics [ONS] 2023). A stillbirth is described as a baby born after 24 weeks gestation that did not breathe or show signs of life. In England and Wales, the stillbirth rate in 2021 was 4.1 stillbirths per 1,000 total births, while the neonatal mortality rate (the death of an infant aged under 28 days) was 2.7 deaths per 1,000 live births (ONS 2023).

**Bereavement and health visiting**

The National Institute for Health and Care Excellence (NICE) (2017) guidelines on end of life care for infants emphasise the importance of healthcare professionals providing bereavement support for families. In addition, the National Bereavement Care Pathway specifically identifies that health visitors are a vital source of ongoing support for bereaved parents (Stillbirth and Neonatal Death Society [SANDS] 2022).

Continuity of support from healthcare professionals following a parental bereavement can reduce levels of anxiety and grief for parents, and it is crucial that they have a single named professional to turn to, with health visitors usually providing this role (Johnson and Langford 2015, PHE 2021, Department of Health and Social Care [DH] 2022). Health visitors are the lead named professional until a child is aged five years (PHE 2021), making them ideally placed to provide support to families following bereavement (Noakes 2017).

The death of a child has a devastating and lasting effect on families, causing the most intense grief (Kersting and Wagner 2012). Compassion and consideration are required by healthcare professionals to assist these families (Boynton 2018); if health visitors approach the task with empathy and sensitivity, they are in an ideal position to provide front-line support to the whole family (Noakes 2017). This includes supporting parents who have lost a child through stillbirth or neonatal loss but who then become pregnant with what is referred to as a ‘rainbow baby’ (a live baby born after a previous miscarriage, stillbirth or neonatal death; the term refers to the return of hope engendered in the parents by the prospect of another child) (Tommy’s 2024).

**Local services**

The Ockenden Report (DH 2022), which examined the maternity services at Shrewsbury and Telford Hospitals NHS Trust (SATH) between 2000 and 2019, identified many failings, such as a lack of adequate monitoring and maternity care resulting in the deaths of multiple babies. The author’s health visiting team serves the same population as SATH (parents will deliver their babies at SATH but are then looked after in the community by health visitors commissioned by Shropshire Community Health NHS Trust). If parents in this population have a rainbow baby, they sit within the author’s health visiting team caseload.

**Gaps in the service**

Following the publication of the Ockenden Report (DH 2022) it was noted that there was a gap in the service locally, where health visitors were not supporting parents following the birth of a rainbow baby to their full potential, despite being well placed to do so (Noakes 2017). As a result, it was vital that the author’s health visiting team adapted to these families’ needs using a trauma-informed approach, which involves attempting to understand how an individual’s previous trauma can affect their health and well-being (Newland et al 2022). Furthermore, it is vital that clinical commissioning groups ensure that services are commissioned appropriately to include grief and loss support for the parents of infants who have died (NICE 2017). Timely intervention such as early support from health visitors is known to significantly reduce the need for resources in the future; for example, parental grief at the loss of a child can contribute to subsequent mental health issues (Potts 2016).

Following recent maternity reviews such as the Ockenden Report, professionals need to learn from past mistakes and improve the care of families in areas such as multidisciplinary teamwork, workplace culture and providing care with kindness and compassion (Royal College of Midwives 2021, DH 2022).

**Rainbow baby health visiting pilot**

Given the stretched resources of health visiting teams across the UK, it was imperative that the health visiting team in the author’s locality identified creative ways to support bereaved families over and above the mandated health visiting contacts, which it was felt would not be enough to meet parents’ needs. In February 2021, the author presented the trust’s nursing director with the idea for a local rainbow baby health visiting pilot project. The project sought to offer a more extensive schedule of visits for local parents who had experienced the delivery of a rainbow baby. To ensure these families were not lost among

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**Key points**

- The provision of trauma-informed, consistent support to the parents involved in the pilot enabled them to enjoy ‘being parents’ and develop an attachment to their baby
- Monitoring the baby’s milestones provided parents with reassurance and reduced anxiety
- Ensuring that fathers were included was a vital aspect of supporting the whole family
- The pilot harnessed the potential of health visitors to help parents navigate the grief of losing a child while supporting their joy at having a rainbow baby
the large health visitor caseloads, targeted support would be offered with a named health visitor at the centre of their care. This would ensure tailored support was delivered to these families at regular intervals from the antenatal period through to the child’s two-year review.

After the author’s presentation, the nursing director approved the project and consultations on its format were undertaken with stakeholders such as GPs, clinical psychologists, Donna Ockenden, the author of the Ockenden Report (DH 2022), community midwives, local authority commissioners and staff from the local neonatal unit. Subsequently, quality, equality and impact assessments were completed, along with a business proposal. Numerous presentations were delivered to the trust board, the trust quality committee and the Care Quality Commission, which collectively agreed to fund the pilot.

**Aim**
The rainbow baby health visiting pilot project aimed to demonstrate that a bespoke health visiting service for parents who had previously experienced a stillbirth or neonatal loss and were now expecting a rainbow baby could assist them in navigating their grief while supporting positive feelings about their new child.

**Method**
The pilot took place from December 2021 to March 2023 and was undertaken by the author as a bank health visitor, for two days a week alongside her part-time family nurse role. The author had cared for families who had previously experienced a stillbirth or neonatal death in her previous roles as a midwife and neonatal sister at SATH, had completed a master’s dissertation on bereavement support in health visiting and had undertaken bereavement training with SANDS, which meant she was qualified to deliver the pilot as a specialist health visitor.

The pilot was undertaken within the central Shropshire health visiting caseload (part of the Shropshire Community Health NHS Trust), where the author’s bank health visiting post lay. Significant support was provided by the Shropshire 0-19 public health and family nurse partnership service lead and the central Shropshire health visiting team lead.

Purposive sampling was used to identify a small population sample with the aim of gathering in-depth data (Depoy and Gitlin 2010). Families eligible for the pilot were approached by the referring professional and if the family wanted to take part, they were given a referral form. Referrals to the pilot were received from the central Shropshire health visiting team, SATH’s neonatal unit and SATH midwives. A phone call and home visit by the author were arranged to discuss the pilot fully. Informed consent was gained and the parents were able to withdraw from the pilot at any stage (Polit and Beck 2017).

In addition to supporting the parents through anxiety and monitoring their general mental health, the pilot was designed to demonstrate how a named healthcare professional could provide continuity and consistency of care. It was envisaged that this role could be undertaken alongside the five health visiting core contacts. The pilot aimed to offer the following benefits:

- Individual bereavement support in the family’s home, tailored to their requirements.
- Delivery of intensive trauma-informed health visiting support.
- A named healthcare professional to avoid parents having to repeat their ‘story’ to various professionals.
- Cost savings to the NHS, as families would not need access to other professionals or NHS services.
- Promoting trust between parents and their infant to develop bonding and attachment (Martland 2014).
- Support for the health and development of the child.
- Provision of a safe space for parents to ask questions.
- Support for parents with feeding, baby cues (understanding how a baby communicates using voice and movement) and baby-led weaning.
- Support for both parents.

Table 1 shows the schedule of visits adopted by the pilot compared with the mandated health visiting contacts the family would otherwise have received.

**Evaluation**
The rainbow baby health visiting pilot was evaluated using a survey, which was emailed to families due to their geographical spread. The survey comprised a mix of 27 open and closed questions (Gelling 2015). The questions focused on all aspects of care the parents received during the pilot, including those they found most beneficial, how the pilot service could be improved and whether it benefited both parents. Anonymity was maintained so participants could not be linked to their data. Confidentiality was also ensured, which was especially important due to the small number of respondents and the rich descriptive data (Polit and Beck 2017). The data were analysed using thematic analysis.
Findings
Five families took part in the pilot, all of whom had previously experienced a stillbirth or neonatal loss and were expecting a rainbow baby. While they had received extra support from SATH during their pregnancy, they were concerned about the limited support they would receive following the birth and this was a significant cause of anxiety. All five families completed the survey, providing a 100% completion rate.

In the open-ended question section of the survey, one respondent stated that the service they received was ‘above and beyond, we are so grateful and could not ask for any more’. Another discussed how they had not been sure what to expect from the pilot:

‘It exceeded my expectations. I wasn’t sure what to expect, but my health visitor is a great source of knowledge. She put my mind at ease about things that were normal and when there was a reason for concern, she was quick to arrange a referral, for example to the physiotherapy service when the baby had a torticollis [asymmetrical head or neck position].’ (Mother, family 2)

All the respondents felt reassured and supported by having regular visits from the same health visitor. This continuity of care spared them the trauma of repeating their story to numerous healthcare professionals, enabling them to develop a trusting relationship with their health visitor.

The provision of targeted support enabled the parents to enjoy ‘being parents’ and develop an attachment with their baby, having a positive effect on the mental health of the whole family. The respondents related how their anxiety was kept at a lower level due to being able to discuss their concerns with a named health visitor who they trusted.

Monitoring milestones
When a child’s development is monitored regularly and on schedule, this supports their cognitive, social and emotional development and prepares them for school; it also provides a potential long-term cost saving for the taxpayer by contributing to the child’s future educational attainment, health and life chances (DH and PHE 2018).

As part of the pilot, frequent questionnaires and reviews aimed at assessing the child’s stage of development were undertaken to reassure parents that their baby’s development was on schedule. In one example, when a baby required a physiotherapy referral this was arranged in a timely manner by the health visitor, which saved the parents having to contact their GP. This reduced the parents’ anxiety and ensured that any issues were dealt with promptly. Two of the respondents commented:

‘It was helpful to have advice and be reassured of the milestones and development targets our baby was reaching. To have information that supported his development in the best way has had a very positive impact on his overall achievement.’ (Mother, family 5)

‘The health visitor always made appropriate suggestions for our baby’s age to help with development.’ (Mother, family 3)

Some of the babies were delivered preterm and their development could be closely monitored because the health visitor was visiting the family more often than if they had been part of the usual health visiting service. One respondent reported that their parenting journey would not have been as positive had they not received the support from the pilot:

‘We were given advice, information and reassurance, which due to them being premature can sometimes vary.’ (Father, family 4)

Trusting relationships
The pilot provided respondents with valuable time and space to talk about the baby they had lost. They were grateful that they had a trusting relationship with the health visitor, with whom they could talk freely, enabling them to focus on being parents (Martland 2014). Respondents reported that without the pilot, their parenting experience would have been ‘very different and not as positive’ and that ‘without the support of the service I may have had postnatal depression’.

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<th>Table 1. Comparison between the mandated health visitor visiting schedule and the pilot schedule</th>
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<td>Mandated health visitor visiting schedule</td>
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<tr>
<td>Antenatal visit</td>
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<td>10-14-day new birth visit</td>
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<td>Six-month contact visit</td>
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<td>18-month review</td>
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Having a safe space enabled respondents to ask questions that they may not have been able to ask other professionals. One respondent reported that:

‘No question was too silly, no judgement, just a caring, personalised, regular continuity of support; someone to give advice and listen to our worries.’ (Mother, family 1)

In addition, there were situations where the pilot meant that support from other healthcare professionals was not required as much as it might have been with the universal health visiting service. For example, some of the respondents felt that they did not have to access their GP or mental health services as much as they might have done if they had not been part of the pilot. Furthermore, one of the respondents said she did not need to resume antidepressants due to having the additional support of the pilot.

Source of support

An important factor that it was not only mothers who were supported, as families can comprise a variety of significant caregivers (Boddy 2019). In the pilot, each family comprised a mother and a father, and by including the fathers it was hoped that there would be a corresponding positive effect on their mental health. Anxiety disorders are common for new fathers, with a prevalence rate of 4-16% in the antenatal period and 2-18% postnatally (Boddy 2019).

The UK’s health visiting service, despite being designed for the whole family, is often viewed as a mother-and-baby service by the public; as a result, many men do not engage with health visitors, which may disadvantage fathers who have an important role in the health of their children and of future generations (Menzies 2019).

It was reassuring, therefore, that both parents in each of the families felt supported by the pilot and that the fathers felt included. One respondent commented:

‘We were given lots of information and support to support our parenting in many ways. From demonstrations to verbal advice, messages, signposting us to directions of further telephone numbers, websites and leaflets for advice and full NHS guidance and support information. We could not have asked for more.’ (Father, family 4)

Source of support

The findings indicated that all five families had a high regard for the support they had received from the pilot. All the parents stated that they would recommend the service to other families in their situation, because without it they would have found themselves sidelined by demand for the local health visitor caseload. The support provided by the pilot was a factor commented on by many respondents:

‘I think anyone who has sadly lost a baby would feel extremely supported by the rainbow baby service. It is a service we were very lucky to have. It has changed our lives as parents by providing a continuity of help, advice and support to increase our confidence and knowledge. It has developed us as parents in providing the best outcomes, well-being and support for our baby. It has helped us in so many ways. It has been invaluable.’ (Mother, family 1)

‘The rainbow baby pilot made us better parents and increased our confidence.’ (Father, family 5)

‘It has made our experience of becoming new parents after a stressful time a lot easier, changing our lives as parents.’ (Father, family 3)

One of the respondents summarised the feelings of the whole group:

‘A service that as parents we will forever be grateful for; I could not be the mummy I am today without all the help and support.’ (Mother, family 1)

Discussion

During the pilot there was only one missed appointment, an important level of continuity considering that missed appointments cost the NHS millions of pounds every year (Ireland 2022). The pilot also reduced the amount of times families had to access other healthcare professionals, thus reducing the number of times they had to repeat their story.

The pilot provided compassion and trauma-informed care and emphasised the importance of having a single named professional responsible for the parents’ management. Gold (2007) suggested that consistency is essential to ensuring that all healthcare professionals are aware of a parent’s loss and thus avoid inadvertent insensitivity and the risk of re-traumatisation. In a systematic review, Gold (2007) found that the most distressing behaviours experienced by parents after the death of a child were healthcare staff’s lack of awareness of the event or avoiding providing support.

A literature review by Noakes (2017) emphasised that there is little bereavement support offered to parents through the health visiting service following the loss of a baby, despite health visitors being ideally placed to provide such support. The pilot described in this article, therefore, provided a unique
service, harnessing the potential of health visitors to help parents navigate the grief of losing a child while supporting their joy at having a rainbow baby.

The pilot also provided a template of a service that could be replicated by other health visiting teams across the UK and integrated alongside the mandated contacts. Services that follow the pilot model could also remove a complex caseload of families who would require targeted support from the regular health visiting caseload. This could save health visitors time and resources and reduce the pressure on staff.

Limitations

The pilot was undertaken by the author as a bank health visitor two days a week, therefore it could only be delivered on fixed days. However, the parents were usually able to accommodate this. In addition, funding was constrained, so the pilot had to be delivered from the limited Central Shropshire health visiting bank budget. As a result, only five families were included and the criteria for accepting families onto the pilot was very strict. Therefore, the findings need to be treated with caution.

Although it is important to develop a trusting relationship with parents in the antenatal period (Christie 2016), two of the families in the pilot were not visited by the author at this time as the mothers gave birth prematurely. However, the author still managed to develop a trusting relationship with these parents as the pilot progressed. The pilot only included parents who had previously lost a baby to a stillbirth or neonatal death, primarily because these were the only families who were available during the pilot timescale. This was despite the original inclusion criteria encompassing families who had experienced a maternal death or lost a baby during a multiple birth; this is a potential area for further research.

Conclusion

The parental feedback received on the rainbow baby health visiting pilot was overwhelmingly positive, showing that the service enhanced the lives of parents. The pilot also demonstrated that by practising trauma-informed care, health visitors can support positivity in parents expecting a rainbow baby. Health visitors should be supported by their trust to deliver a rainbow baby service alongside their mandated health visiting caseloads.

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