



Multiple Failings

Parents' of Twins and Triplets Experience
of Pre & Post Natal NHS Care

ANALYSIS BY DR. ERIKA FRASER

Introduction

The 2008 Tamba Health and Lifestyle survey collected the views of 1,363 mothers of multiples who had their babies in the last five years (1,298 mothers of twins and 68 mothers of triplets). The online survey asked 17 questions on levels of antenatal care, parent education, nutrition, postnatal depression and lifestyle and routines in the first year.

The survey found that many mothers have a positive experience of the health professionals that support them through their pregnancy, and highly rated the care provided by Special Care Baby Units. Indeed, their experiences have contributed to Tamba's Good Practice Recommendations for Parent Education at the end of Section 2.

However there are several issues of great concern that must be addressed across the NHS to ensure the health, wellbeing and happiness of the babies, their mothers, and their families as a whole. These issues include:

- Insufficient expertise on multiple pregnancies and a lack of continuity in antenatal care, which sometimes results in parents being given conflicting advice on the health of their unborn children. 14% of respondents felt these factors compromised the wellbeing of both mothers and their babies. Further information is provided in Section 1.
- Just one third of respondents are offered multiple-specific parent education sessions. This is very troubling as – whilst many who attend these sessions find them very useful – those mothers who do not often express feelings of being unprepared or ill-informed for the birth and how to cope with their babies. The Tamba survey also indicates that this group of women is more prone to develop Postnatal Depression. Further information is provided in Sections 2 and 5.
- Insufficient advice on nutrition for multiple pregnancies (nearly nine out of 10 respondents received no specific advice on how to eat properly). The poor quantity and quality of hospital food available for nursing and expectant mothers, some of whom were hospitalised for weeks before the birth, is also an area of concern. Further information is provided in Section 4.
- With at least one baby entering special care in the case of 44% of twins and 91% of triplets, the Tamba survey reveals examples of exceptional standards in special care units across the country. Worryingly, however, one in every eight mothers are separated from their babies whilst in special care, causing them trauma, pain and intense worry. More worrying still, the survey data suggests that the situation is getting worse. See Section 4 for more information.
- The rate of Postnatal Depression is far higher amongst mothers of multiples (17% compared to 10% of all women with children under the aged of one). Significantly, the survey found that mothers of multiples who experienced PND are less likely to have attended parent education classes, more likely to have received poor quality antenatal care; more likely to have developed pregnancy complications; have less sleep; receive less help from friends and family and are less likely to be a member of Tamba. (See Section 5 for more information).

In view of the harmful effects of PND, this finding adds further weight to the importance of adopting Tamba's recommendations, as outlined in Section 9.

1

NHS Antenatal Care

Mothers of multiples have a mixed experience of antenatal care by the NHS (see table below). Many rated health professionals (consultants and midwives) highly. However serious concerns are raised regarding gaps in advice on feeding multiples and a worrying lack of access to multiple-specific talks and/or classes, with 14% of respondents believing that the quality of antenatal care put the health of themselves or their babies at risk. Concerns are also raised regarding continuity of care and limited expertise on multiple births, as we set out below.

Q9: Respondents' ratings of their NHS antenatal care

| | Excellent | Very good | Good | Fairly good | Poor | Response count |
|--------------------------------|-------------|-------------|-------------|-------------|-------------|----------------|
| Advice given by consultant | 30.2% (401) | 26.8% (355) | 19.4% (257) | 14.5% (193) | 9.1% (121) | 1,327 |
| Advice given by midwives | 18.5% (247) | 26.5% (354) | 23.4% (313) | 18.5% (248) | 13.2% (176) | 1,338 |
| Advice on feeding babies | 11.3% (151) | 15.1% (203) | 20.7% (278) | 21.3% (286) | 31.6% (424) | 1,342 |
| Access to screening | 22.8% (300) | 24.0% (315) | 24.8% (326) | 15.2% (200) | 13.2% (173) | 1,314 |
| Access to parentcraft sessions | 7.5% (99) | 9.8% (129) | 17.2% (227) | 18.1% (239) | 47.5% (627) | 1,321 |

Respondents give the highest ratings to consultants, with over half (57%) saying the antenatal care by consultants is very good or excellent. Only 9% of mothers said the advice given by consultants is poor.

Midwives are rated less highly with less than half (45%) believing midwives' advice to be very good or excellent. However, levels of dissatisfaction with midwives is still low (13% rated 'poor'). The highest levels of satisfaction are for hospitals with specialized midwife expertise; Queen Charlottes and RVI Newcastle are two hospitals that respondents mentioned as having dedicated midwives with experience of multiple births Helga and Sandra respectively: "It made us feel very special and reassured, not concerned".

Access to screening is also rated reasonably well, with 47% rating it very good or excellent. Some sonographers' lack of experience scanning multiples caused confusion, however:

"I was constantly being told that they were not growing at scans and the consultant finally scanned me and told me everything was OK to put my mind at rest - I think that the sonographers need more training scanning multiples, as I know I was not the only parent with twins that they worried unnecessary".

"Was not offered a scan at 36 weeks as they were too busy that week and it turned out one of my babies had stopped growing."

Of concern are low survey ratings for the quality of advice on feeding, which has proven beneficial health outcomes for mothers and babies. Only 26% of mothers said they were given excellent or very good advice, and a third (32%) rated the feeding advice as poor:

"The medical care was excellent but the initial pressure to breastfeed placed too much pressure on me which affected my mental health. The midwives were simply

too busy to stay with you to help you breastfeed and the breastfeeding counsellor was over-zealous, calling the necessary top up feeding with formula 'poison' which sends completely the wrong message to new mothers trying to cope with breastfeeding twins"

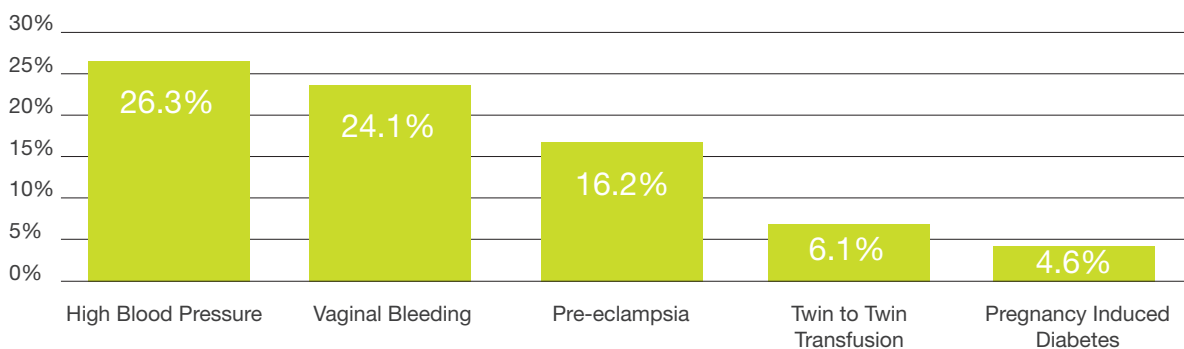
"Very poor breastfeeding advice led to problems that never really went away although we bf with bottle top-ups for five months. Proper advice would have helped a lot"

"No-one seemed to have a clue on how to breastfeed prem multiples. I had large boobs & tiny babies & never successfully breastfed at least in part because special care staff refused to cup feed saying it took too long & they didn't have time."

However, access to parentcraft sessions received the lowest rating on antenatal care. Only 17% of mothers had excellent or very good experiences of antenatal classes and/or talks, with almost half (48%) of mothers saying access is poor. The lack of information provided by NHS hospitals on multiple births is an issue of serious concern and is expanded on in Section 2.

The most common pregnancy conditions experienced by women are high blood pressure (26%) and vaginal bleeding (24%), followed by pre-eclampsia (16%), Twin to Twin transfusion (6%) and pregnancy-induced diabetes (4.6%), as set out in the table below.

Q11: Percentage of respondents who developed pregnancy-related conditions



Although most mothers are satisfied that a good standard of antenatal care is given and felt reassured that they were in 'safe hands', approximately one quarter of mothers provided detailed comments about concerning antenatal experiences.

Indeed, a significant minority (14%) believe that the quality of antenatal care put the health of themselves or their babies at risk. A further 10% are 'not sure' if they have been put at risk by poor quality care.

Issues of being 'forgotten' or 'alone' are frequently raised by respondents:

"I kept getting lost in the system, was refused appointments I was asked by my consultant to make. No one booked me in for a C-section even though both my twins were transverse at 36 weeks. No one seemed to care, consultant wasn't interested and I never had a midwife. I was also refused blood tests for my underactive thyroid which was supposed to be checked regularly while I was pregnant; it was only done once when I demanded it."

"The consultant I had did not give a jot and I felt totally isolated"

A lack of continuity in antenatal care is a common problem expressed by mothers in the survey, some of whom saw a different health professional at each appointment:

“Consultant care was very poor - we had to insist on seeing the same consultant towards the end of pregnancy as we were being given totally conflicting advice when we were seeing different consultants”

“Had a fairly straightforward pregnancy but never saw the same Dr @ hosp so no continuity and felt that my care was very ‘medicalised’ - very ‘conveyer belt’ & no real opportunity to discuss issues or what to expect.”

These gaps in providing continuous antenatal care can be partly explained by more widespread failings in NHS maternity services, in particular low staffing levels.

However, mothers also raised concerns about the lack of expertise on multiple births and frequently received confusing or mixed messages from health professionals, particularly about twin-to-twin transfusion syndrome (TTTS):

“No info about multiple births given until halfway through. Felt very much left in the dark. When we did get more care the OB was rarely there and other doctors/ midwives had poor knowledge of multiples, resulting in being told by a registrar that one baby was not growing and we would need to deliver early (we were at 29 weeks). OB saw us a scary week later and found all was fine. I completely slipped through the net with regards to parentcraft classes (multiple OR single) and with info on feeding. Basically I just saw too many DIFFERENT people. No continuity at all”.

“I felt very depressed throughout a large part of the pregnancy because of the total lack of relevant information that was made available to me. I kept being told that I was a ‘high-risk pregnancy’ - because I was expecting twins - but was then offered less care, in many respects, than someone with an uncomplicated singleton pregnancy would have received - no community midwife, no access to screening tests, no continuity of care, no access to parentcraft classes. I was not even able to see a consultant until I was 36 weeks pregnant.”

Mothers also complained in the survey about the way in which information is communicated, with health professionals sometimes creating unnecessary anxiety by over-emphasising the risks and complications of multiple births:

“At 7 weeks pregnant I was told that there was only a 40% chance my babies would survive as they were monoamniotic. At 12 weeks I was told this was a misdiagnosis which caused me undue worry ... too much scare mongering.”

“Over-cautious health professionals caused unnecessary worry for me during my pretty much perfect pregnancy. I felt most of this was due to the pressure the NHS is under from the threat of legal action if mistakes are made.”

Similarly, mothers expressed concern about overly rigid hospital policies on multiple births and feeling unsupported with natural births:

“I felt that pregnancy and birth were over-medicalised and I was not given the freedom to labour the way I wanted and felt was best for myself and my babies (e.g. upright, in water, mobile). My consultant continually treated my pregnancy as problematic despite the fact that I had no complications whatsoever, which made me feel anxious and upset. The provisions that my health care providers deemed

necessary for labour such as a prone position and attempts at continuous monitoring made the experience more difficult and prolonged and generally far less satisfying and positive than it could have been.”

Despite the high-risk nature of multiple births, mothers do want to be treated with dignity and given a voice in their antenatal care and labour. Comments in the Tamba survey reveal that a considerable proportion of mothers are very proactive in their approach to the pregnancy and birth: reading relevant research and books; sharing experiences with other multiple mothers on the Tamba messageboards and forums; repeatedly requesting access to parent education; demanding continuity of care or to be seen by health professionals with experience of multiple births; and changing consultants or even hospitals if necessary. Nevertheless, not all mothers (and especially first-time mothers) know what to expect and many feel unable to articulate their concerns or ask for the level of antenatal care they believe necessary.

To provide for better outcomes in the case of multiple births, Tamba recommends that all expectant mothers of multiples should be seen within six weeks of identification of multiple pregnancy by a designated consultant with experience of multiples.

2

Parent Education

Only one third (36%) of mothers were offered multiple-specific parent education session(s), most of which were one-off sessions organised by the hospital. The majority of respondents who attended sessions found them extremely useful, especially tours of the hospital and talks by representatives from local twins clubs.

(At the close of Section 2 we draw on their feedback to provide examples of good practice that should be adopted as standard practice across NHS hospitals). However, it is regrettable that two thirds of mothers were unable to access these talks. It is also concerning that in several hospitals these sessions are threatened by hospital funding being withdrawn or specialist midwives moving away, as we set out below.

A common problem raised by respondents is the lack of information given by hospitals about when multiple talks are held. As one respondent commented: “we had to find out about it, rather than being informed”. Some mothers-to-be described repeatedly requesting multiples education, but only being offered a place on a class after the babies had been born! Those mothers who did not attend talks or classes often expressed feelings of being unprepared or ill-informed for the birth and how to cope with their babies. (This is deeply worrying, as the survey also found that mothers who developed PND were less likely to have attended parent education classes -see Section 5 on postnatal depression). For example:

“The first couple of months were really really tough; at one point I was struggling to cope and had a lot of health visitor input, luckily enough one of them was a multiple mother herself. I really do believe that if I would have had parentcraft aimed at multiple parents I would have felt more adequate to cope, it was like plunging off a cliff!”

Talks are often too irregular or arranged too late in mothers' pregnancies:

"We were offered a special antenatal class but the only class was after my due date as the class was not run regularly. We were therefore unable to attend."

"2 two-hour sessions, but they were very late in my pregnancy - at weeks 36 and 37. Most expectant mothers of twins find it difficult to get out and about much at this stage, or they have already given birth. They should have been much earlier on during the pregnancy to give me more time to prepare."

In several hospitals (e.g. Southmead, Ipswich, Brighton), multiples sessions are threatened by hospital funding being withdrawn or specialist midwives moving away.

A few triplet mothers thought the talks are too twin-focused:

"I felt as much of an outsider there that I would have done at an ordinary antenatal class, I was singled out for being the only expectant mother of triplets and did not find it beneficial at all. The whole thing was based around twins".

Good Practice - Parent Education

- Be sensitive when discussing multiple births. Although the risks involved in multiple births can and should be discussed, the aim should be to reassure, inform and prepare parents rather than increase anxiety by highlighting worst-case scenarios.
- Provide hospital-specific statistics for the last few years on the proportion of caesareans (and the % which are elective or emergency), proportion of labours induced, average birth weights, time of delivery in weeks, and proportion of babies in special care. However, talks should be more than just explaining hospital policy on multiple births.
- Invite member(s) of local twins club to give a talk and put expectant mothers in contact with groups for multiples.
- Facilitate local friendships and support networks between expectant mothers, for example: (1) passing a piece of paper around with e-mail addresses; (2) arranging a date for a get-together for mothers in the locality or at a coffee morning at the local twins plus club.
- Provide a tour of the delivery suites and SCBU
- Ensure sessions are regular (at least once a month) and multiple mothers are offered the session(s) early in pregnancy, in case of premature births and lack of mobility in later months – ideally around 26 weeks
- Publicise talks for multiples – it should be hospital policy for the midwife to book mothers into a session as soon as they find out they're expecting multiples
- Provide practical information about how to cope after the twins are born, for example breast/bottle feeding, sleeping, changing nappies, postnatal depression
- Allocate time at the end for a Q&A session
- If possible, session(s) should be lead by midwives or doctors with experience delivering multiples.

3

Nutrition

Nutrition is important in all pregnancies, and yet almost nine out of 10 women (87%) received no specific nutritional advice for a multiple pregnancy. As one woman commented: “I got no support at all about ‘caring’ for me and nutrition. I think health professionals assume that someone else will cover it - and it falls through the gap with high risk multiple pregnancies.”

Some women are given vague recommendations to eat ‘healthily’ or ‘keep your energy up’, for example a survey respondent was warned to “have a good diet as twins are parasites!” However, mothers are generally offered little advice specific to multiple pregnancies. Others feel this lack of tailored dietary advice contributes to poor outcomes for their babies and themselves:

“No, and I think not eating enough and lack of weight gain was a factor in my premature delivery. I only found this out afterwards. I was just given standard info for a singleton pregnancy: i.e. no need to eat more before 3rd trimester (which my pregnancy barely reached!)”

“I was not told that there would be extra pressures on my iron level with twins and needed blood transfusions to compensate as I wasn’t prescribed iron at any time during the pregnancy.”

Only 13% of women are given specific advice on nutrition for a multiple pregnancy. The most common recommendations are to take extra folic acid and iron tablets. Several women complained about the ‘huge’ iron supplements and associated nausea: “they upset my stomach so I substituted this for iron rich fruit and vegetables.”

A minority of mothers (less than one in 10) are given detailed information about ideal diets for multiple pregnancies, for example:

“Told to try to put on weight (for babies) in 1st two trimesters to give them good survival chances if born early. Told to eat protein, and esp. in form of dairy foods (link to reduced pre-eclampsia if consuming calcium). Told to drink lots of water to reduce chance of early contractions. And to watch iron levels (so red meat & leafy green veg). I ate loads of fruit & veg and snacked on toast & marmite, cheese and smoothies

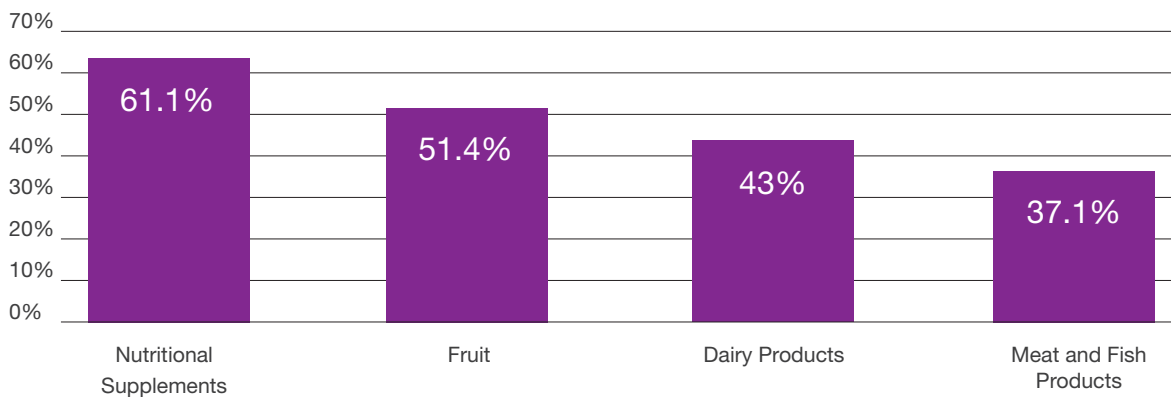
Women who had received nutritional advice tended to have been given this as a result of experiencing pregnancy-related complications, particularly hyperemesis (severe nausea), gestational diabetes, anaemia and pre-eclampsia. A few of these respondents had been referred to the hospital dietician – an example of good practice that should be replicated where possible.

Another issue is the poor quantity and quality of hospital food available for expectant mothers (some of whom were hospitalised for weeks before the birth) and nursing mothers:

“Food in the hospital was appalling for a breastfeeding mother of twins having just undergone a caesarean. I have read that a mother of twins should be eating up to 4000 calories a day and the portions were very small with no extra food available, not even a biscuit with a cup of tea”

Expectant mothers appeared to be aware of the benefits of a good nutrition for pregnancy outcomes, with over half of survey respondents spending additional money on nutritional supplements (62%) and fruit (51%). As the graph below shows, 43% of women also spent money on dairy products and 37% on meat and fish products.

Q13 Percentage of respondents who spent additional money on the following aspects of diet during pregnancy



Many women also proactively read about nutrition in ‘American books’ or on the internet. Specific recommendations on multiple pregnancies including menu ideas and recipes would be welcomed by pregnant mothers. One respondent stated:

“All literature available on NHS (that I found) was geared towards having one baby and NOT the differences of having two or more.”

Recognising that better nutrition promotes better outcomes, Tamba recommends the following steps be taken across the NHS:

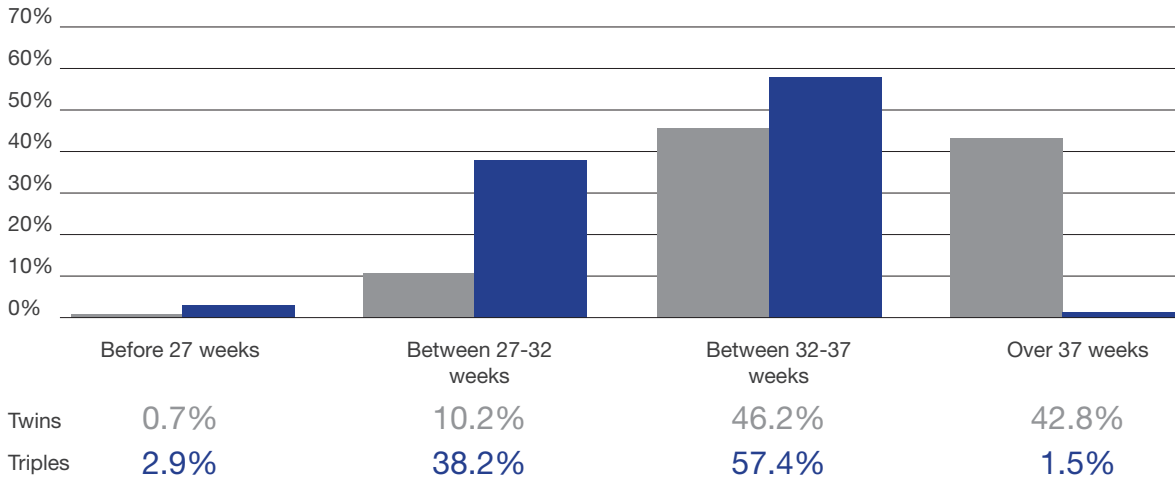
- Midwives to offer ‘tailored’ nutritional advice to mothers of multiples during early antenatal appointments to ensure better outcomes. In the case of pregnancy-related complications mothers should have access to a hospital dietician.
- Hospitals to ensure sufficient food portions for expectant mothers of multiples and nursing mothers
- Each hospital to have a dedicated midwife on maternity wards with experience of supporting women with breastfeeding multiples.

4

Special Care

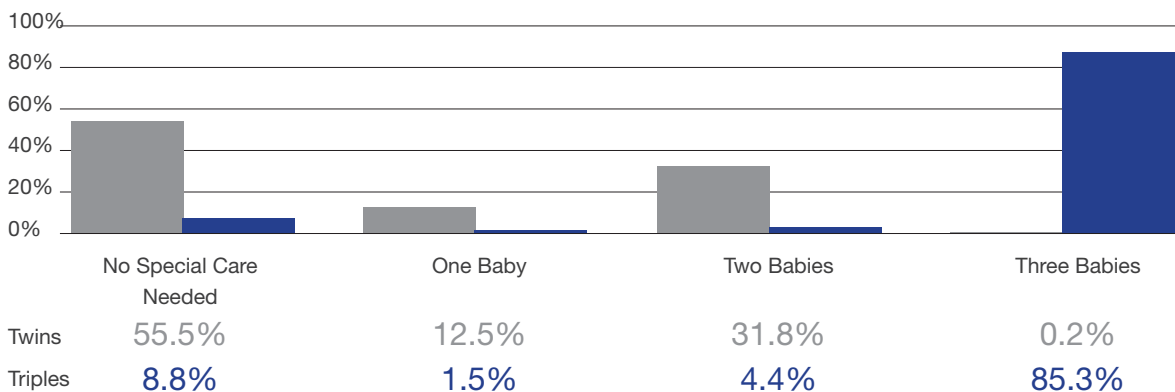
Multiple pregnancies are generally less likely to carry to full term (which is typically 40 weeks for singleton births). Just 43% of twin pregnancies and 1.5% of triplet pregnancies lasted over 37 weeks (The graph below gives a detailed breakdown of when respondents' babies were born). As we set out below, a significant proportion of multiple babies go into special care. This brings with it particular challenges, and in some cases trauma, for their families. In particular, it is worrying to note that hospitals appear to be increasingly unable to accommodate families together when babies require special care – this issue requires urgent examination and redress.

Q3. When multiples are born



Just under a half (44%) of mothers of twins said at least one of their babies had been in special care. Unsurprisingly, this figure was much higher (91%) for mothers of triplets. Indeed, 85% of mothers of triplets had all three babies in special care, 4% had two babies in special care, and 1.5% had one baby.

Q5: Percentage of respondents whose babies needed special care



The Tamba survey reveals examples of exceptional standards in special care units across the country. Hospitals praised for being supportive included: Birmingham Women's Hospital; Stepping Hill Hospital in Stockport; Wycombe Hospital; Ipswich Hospital; Whittington Hospital; Dorset County Hospital; Taunton Hospital; Barnet Hospital; Poole Hospital; Chelsea and Westminster in London; Bangor Hospital; Raigmore, Inverness; Warwick Hospital; and St Michaels' Maternity Hospital in Bristol.

Characteristics of good practice include regular communication between parents and health professionals and designating space for mothers and 'healthy' siblings to stay, which is very important to help establish breastfeeding.

Although 87% of families with babies requiring special care were able to stay together with their siblings and parents, a significant proportion (13% or one in every eight mothers) were separated from their babies. Regions where respondents had experienced the highest levels of separation were in the South-West (26%), East (22%) and Wales (19%).

For families who are separated from their baby (or babies), the experience can be traumatic:

"The babies were taken to another hospital within hours of the birth but I only got to follow them over 24 hrs later when my husband threatened the hospital management with legal action, press involvement etc. I spent a very lonely night all alone in a room with a morphine drip and three Polaroid pics (from the other hospital). My husband was with the boys as we really did not know if they would live. I just spread the pics on my lap and sat up all night looking at them. It is a very sad memory."

"I was discharged with one baby and lived 1.5 hours from the hospital. Having had a caesarean, I couldn't drive and was told that as my other daughter was a prem baby and still just 5lbs it was inappropriate to drive with her in the car for that amount of time and could damage her spine etc. I was then unable to visit my other baby in the unit for 5 days until she was transferred to a 30min drive away. At all times I was told to look after my well baby and I really do not feel I had the support I needed or encouragement to bond with my ill baby. I live with constant guilt for abandoning my poorly baby but I was given no alternatives. I don't wish for anyone else with twins to go through what I went through."

Comments in the survey suggest that if respondents hadn't argued so passionately to keep their babies together, this figure for separation could have ended up nearer 20% than 13%.

For example:

"Had to force the issue and insist. Went into labour in Birmingham at 28 weeks, was asked to deliver immediately, send one baby to Manchester, one to London and me to the Welsh border! I flat out refused and lay waiting for 10 hours until a place was found for us in Norwich and Norfolk University Hospital. Then had to endure a 4 hour ambulance ride at 2 am from B'ham to Norwich in great pain and fear."

"We were moved from UCL where the babies were born to Chelsea and Westminster the day after and then on to the Princess Royal in Bromley. We were constantly having to argue the case for the babies not to be moved separately when one cot became available in other hospitals and it was extremely stressful."

"We were told that one baby may need to be moved to a different hospital (Watford General) for budgetary reasons when a special care cot became free in that hospital (being the one to which we were originally booked but which was full when the babies were delivered). We refused to sign the consent form allowing this to happen until we could be guaranteed that both babies would be moved together."

Nevertheless, the fear of whether their local hospital will be able to 'accommodate' them during labour and worries about possible separation from their children afterwards can be acute for pregnant mothers:

"This was extremely worrying. My planned caesarean was delayed by five days because of other emergency births filling SCBU beds and by the fifth day of delay, one of my babies was showing signs of distress so I then became the emergency. It was a case of running to get on the operating table and claim the SCBU beds for my three and it was not until I actually received the epidural was I assured that my babies would all remain in the same hospital. They were born at Kings College but at one point there was talk to transferring one to Cambridge and another to Leeds!"

For mothers recovering from exhausting and traumatic births, hospitals can seem vast and their babies far away: "We were in the same hospital but as I was unable to walk I did not see the baby for the first three days of his life". Several respondents expressed pain and regret about being separated from their twins, despite being in the same hospital:

"One of my sons was in special care for a week, the other for three weeks. For the first two weeks I was in a different building from the special care unit, and initially I was only allowed to visit special care in a hospital wheel chair, and accompanied either by my partner or a member of staff which made visiting very difficult as neither wheelchairs or staff were readily available. After a week one of my sons moved with me into the post natal ward and I struggled to breastfeed him, express for the second, and get over to special care within a three hourly feeding routine ... the whole experience was extremely difficult and upsetting."

Barriers to seeing their babies included:

- Lack of mobility following Caesareans;
- No staff or wheelchairs available to help;
- Further siblings waiting at home;
- Being made to leave the 'healthy' twin behind on the ward while they visited the other sibling in SCBU.

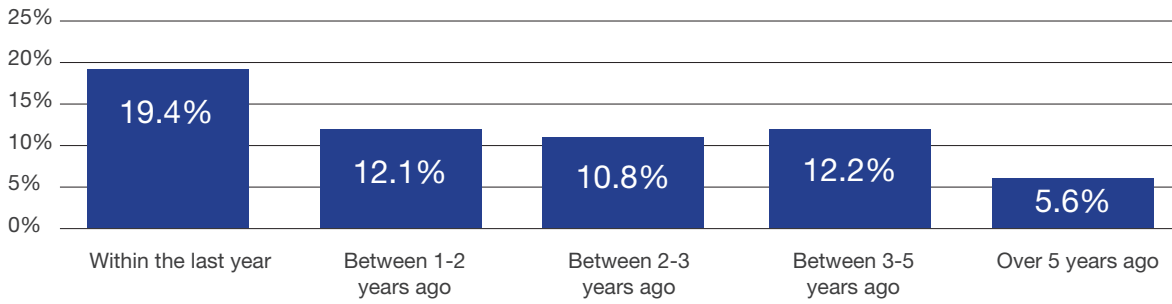
"I was not permitted to take my 'well' baby into SCBU with me to see my daughter who was in special care - this was extremely stressful as I constantly had to leave one baby on the ward alone while I visited SCBU, and had to breastfeed them separately, meaning I never got any rest. I do not think the hospital has thought about this aspect of care and do not think it is conducive to the wellbeing of mother or babies, or safe for the baby left on the ward alone."

Keeping multiples together and providing accommodation for mothers near their babies is not only important for emotional well-being and mental health, but also critical for establishing successful breastfeeding:

"I was able to stay with them in Salisbury thanks to a shared room in League of Friends accommodation on site. This helped enormously to establish breastfeeding, though I was almost sent home (25 miles away) before the babies were discharged as I was no longer in the care of the hospital. Fortunately when I pointed out that this would be catastrophic for their feeding, I was allowed to stay until they were discharged. There appears to be a huge assumption from health professionals that all multiples are bottle-fed or formula-fed from birth. I appreciate that this is much more likely for multiples but there is less support for twin mums attempting breastfeeding."

Worryingly, the survey data suggests that the situation appears to be deteriorating, with hospitals being increasingly unable to accommodate families together when babies require special care. Whereas only 6% of respondents were separated over five years ago, the figure had risen to 19% within the last year (see below).

Q6 Changing percentage of babies who were NOT able to stay together at the same hospital, by year



This situation requires urgent redress. To ensure this happens, Tamba recommends that there should be more investment in special care units so that mothers can be accommodated at their local hospital.

Priority should be given to mothers of multiples, so that mothers and babies are not separated after birth.

Additionally, transitional wards should be built near the special care units so that mothers and babies can stay together.

5

Postnatal Depression (PND)

The Tamba survey reveals that 17% of mothers of multiples have experienced Postnatal Depression (PND), with a further 18% 'not sure'. This is nearly double the widely-reported estimate of 10% of all women with children (including singletons and multiples) under the age of one had received some sort of treatment for PND.

A detailed analysis of the Tamba survey finds no difference between twin and triplet mothers and no statistical link between PND and prematurity, the weight of the babies, whether the babies were in special care, whether the babies were separated immediately after the birth, membership of local twin club and no regional differences.

Interestingly, however, the survey did find the following features of mothers who experienced PND are higher than the average survey response:

- Less likely to have attended parent education classes;
- Received poor quality antenatal care;
- Developed pregnancy complications;
- Less sleep;
- Less help from friends and family;
- Less likely to be a member of Tamba.

Please see the table below for more information:

| Link with postnatal depression: Survey findings where the % for women who had experienced PND was higher than the average for all survey respondents | | |
|--|-------------------|-----------------------------|
| | % experienced PND | %for all survey respondents |
| Had not attended parent education talk/classes | 67% | 64% |
| Believed poor quality of antenatal care had placed babies or their own health at risk | 22% | 14% |
| Developed high blood pressure during pregnancy | 30% | 26% |
| Developed pre-eclampsia during pregnancy | 20% | 16% |
| Developed Twin to Twin transfusion during pregnancy | 8% | 6% |
| Developed pregnancy-induced diabetes | 7% | 5% |
| Experienced vaginal bleeding during pregnancy | 28% | 24% |
| An average of less than 5 hours sleep over a 24 hour period in the first year of babies' life | 61% | 46% |
| No help from family | 14% | 8% |
| No help from friends | 66% | 64% |
| Not member of Tamba | 35% | 32% |

Survey respondents who answered 'Yes' to the question 'Have you suffered from postnatal depression?' have usually been diagnosed by a doctor or health visitor, typically after filling in the Edinburgh Post Natal Depression Scale (EPDS), a short questionnaire with 10 simple questions. Others had self-diagnosed the symptoms and requested confirmation from their doctors. It is also common for family members and friends to notice the signs of postnatal depression and suggest to mothers they should seek help.

The Tamba survey did not attempt to measure the quality of mothers' experiences of being treated for PND and there are undoubtedly positive examples of excellent care by health professionals, for example:

"I had the most superb 'part time' health visitor that really worked above and beyond what was expected of her - without her support and care I am not sure how I would have coped."

"Yes, health visitor and local GP surgery were extremely supportive and kept close eye on me."

However, less than 10% of the 300 comments on postnatal depression in Q14 gave positive feedback about their experiences. A few mothers said they had never discussed postnatal depression with a health professional, never completed a questionnaire or had completed it but the health visitor never came to collect it. Others described how they had to remind the health visitor that they needed to be tested. One respondent wrote: "I do research in this field and my health visitor did not have the EPDS with her at my 6 week visit. She had to return the next day with one when I asked."

Another common problem is weak implementation of procedures for following-up on high scores in the EPDS questionnaire. Mothers with above average scores in the EPDS questionnaire gave the following examples of poor practice:

- Health visitors who promised to drop off some leaflets about PND, but never did;
- Being told by doctors that PND could not be treated when breastfeeding;
- Being told to 'take more time for themselves' without being able to give any advice on how they could make that time as a mother of multiples;
- Not being seen as a priority case because they had older child and came from middle-class professional household.

Some mothers are told to go away and see if the symptoms lasted for longer than 6 weeks. A shorter time period is recommended:

"Did not receive much help from the midwife. As we bought the girls home at Easter, there were days when no-one came. The midwife did the depression/stress test (can't remember the correct name) and it was well over the higher figure. The midwife said she thought it would be higher as I had twins. She said she would test me again in a couple of weeks but did not. It was a couple of months later when she repeated the test which was still in the high levels. I would have thought it was wise to keep in contact with mums who had high stress scores but this was not the case".

New mothers, particularly first-time mothers, frequently express feelings of shame or guilt that they might be affected by postnatal depression. One described being "so determined to prove to people that I could cope". Other women said they 'hid' the signs and tried to fool the questionnaire. It is very important for health professionals and organisations working with new mothers to be sensitive when administering the questionnaire and to communicate the message that mothers are not failures if they feel unable to cope. Professionals need to emphasise that it is alright to struggle with your feelings and children will not be taken into care. Certainly it is not recommended that they should congratulate mothers on "passing the 'tick' test", as was the case with one respondent.

Mothers responding to the survey commented:

“It is very easy to pretend you are ‘coping’. The PND questionnaire is multi-choice so you just answer what you think shows you are doing ok. It is hard to be honest because you feel you will be judged a ‘bad mother’. Not coping is not something women find easy to admit to. It would take time and a very understanding health professional for a woman to admit how hard she is really finding it.”

Although examples of good practice found in the survey included health professionals coming to the homes of multiple families, many respondents identified practical problems accessing PND care for mothers of twins and triplets. For example, some surgeries are not accessible for double-buggies:

“I feel that I am suffering now it hasn’t been picked up and it is made loads worse by visiting baby clinic as they won’t let my push chair in so I don’t get to speak to health visitors as idea of struggling at clinic and having to wait outside on own makes me feel awful I have tried to complain but all I am told is building manager is not v nice and a jobsworth which doesn’t help me at all.”

Mothers also described feeling rushed and unable to discuss complex emotions and mental health issues while struggling with two or more babies in crowded baby clinics and during appointments with GPs.

Some mothers of twins and triplets encountered unhelpful attitudes from health professionals, regarding their PND. These unhelpful attitudes ranged from doctors and health visitors being “in awe of my lovely healthy babies” to dismissive (one woman “even got told that a mother and toddler group would probably ‘cheer me up’ by one mental health professional”). In view of the devastating effects of PND (in some cases mothers self-harmed and contemplated suicide, as we set out below), these attitudes are best avoided.

The survey highlights that health professionals should also be alert to the ongoing challenges of managing more than one baby, with respondents frequently describing the late onset of PND well into, and beyond the first year:

“Health professional said [I was] borderline at a time when I was exhausted. However I believe that PND probably kicked in about 12 month mark when there was no regular contact with health professionals”.

The most common treatment for PND is medication, but much more could be done in the form of emotional support and counseling:

“I was disappointed that all the doctor could offer me was a prescription for antidepressants when what I needed was someone to talk to.”

Another woman described her long wait for treatment:

“Yes I have received good support from my GP but counselling / CBT availability was absolutely dreadful. I have been on the NHS waiting list for 8 months now and have been told I may get an appointment in May.”

The thought of wanting to walk away from your babies was more common than might be expected, having occurred to 59% of respondents (9% experienced this desire ‘frequently’). In some cases, this was simply just a recurring fantasy of booking into a hotel room and having a decent night’s sleep (alone!) However, in other cases the feelings were more acute and overwhelming. A small number (five respondents) had already walked out, but returned. Others felt alone, cried regularly, some self-harmed, and a few even contemplated suicide:

“The reality of being alone with two babies, post-IVF and post-premature birth with no family support was sometimes bleak and relentless. One occasion as I was driving down a particular dual carriageway I found myself fantasising about crashing over the barrier, then at least it would all stop. Somehow the girls wouldn’t be in the car, I didn’t want to harm them but couldn’t see any way to change anything and wanted to stop. I think this was my version of walking out. Suffice to say I didn’t carry it out!”

Mothers who already had children described the difficulties in balancing the needs of their existing children: “I felt so overwhelmed by the twins during the day that it seemed too much to hug her [older daughter] as well”. For a few new mothers, there was a sense that they had been ‘robbed’ of the typical mother-child bond that singletons appear to enjoy:

“I probably actively hated the first 6 months, and the feeling has gradually faded (boys are 15 months at time of writing this) and has taken me a long time to adapt to being a mother of two, and to let go of my ‘single baby envy’ which I suffered with a lot when they were younger.”

“I felt cross that I had had twins because all my friends were blissfully happy with their one baby, going out easily to baby massage classes, swimming etc. I felt that I was always struggling, that I didn’t have time to enjoy my babies or give them the level of intimacy with me that I should because there was always something else that needed doing, it was like a production line of feeding and changing etc. I felt guilty for not being all that happy.”

Feelings of being overwhelmed with PND can be most acute when multiples are ill, even if just colds, teething problems or stomach upsets. When parents of multiples consult doctors or health visitors about their babies’ health issues, it would be good practice for medical professionals to check whether babies’ ill health is impacting on mother’s mental health:

“Once when we had all been ill with colds and stomach upset and at the end of week 4, I felt like enough was enough. We went to the doctors every week with one thing or another and never once did the medical professions appear concerned about my state of mind.”

Having more than one baby suffering from colic appears to be a particular trigger for postnatal depression, for example:

“One day I decided I didn’t want the babies anymore. I wanted to walk over to my local shopping centre and leave them somewhere, I rang my husband [and told him] what I was going to do, and he came home from work to help me. Both babies were colic and I couldn’t cope. Makes me feel upset just typing this.”

The Tamba survey also highlights the ways in which tiredness and lack of sleep contribute to postnatal depression. The middle of the night and early hours of the morning are difficult times due to exhaustion and there is often no-one else awake to talk to (with partners needing to work the next day). Tamba may wish to seek sources of funding and look into keeping the Twinline open beyond 10pm:

“Quite often during the early hours of the morning when one baby still had to be fed, and it was cold and dark, and I wanted to sleep, I regularly cried. Early morning/night feeds could be soul destroying.”

Fathers of multiples may also suffer from postnatal depression, as a few respondents described: “My husband suffered much more than me. He got very depressed”. Another father had to take four months off work to deal with his depression. Related to this, a particular issue arose around family breakdown with fathers unable to cope with the shock of multiples and subsequent PND for single parents of multiples. Support for single mothers of multiples should be high priority, as one woman suggests:

“I am a single mother of 6 month old twins [as well as two older children] - my husband disappeared when we discovered I was expecting the twins, and despite family support, it all tends to get on top of me from time to time. I feel there is not always the professional support available, or specifically aimed at single parents of multiples.”

In view of the overwhelming need for support outlined by parents of multiples above (and particularly the need for support and somebody to talk to in the early hours of the morning), Tamba is seeking funding to make its popular ‘Twinline’ 24 hours a day, 7 days a week.

Tamba also recommends that all parents of multiples should be offered home visits by trained community midwives and health visitors to ensure early identification of PND and continuing support where needed.

Health professionals should be made aware that PND can be triggered when children are ill (especially colic). Doctors and midwives should be encouraged to check if mothers are coping (mentally) while also offering medical advice to children.

6

The First Year

The most time-consuming activity in the first year is feeding, with 80% of respondents spending more than 3 hours a day feeding their babies. Other time-consuming activities are changing nappies and bathing/cleaning/dressing babies. Of course, as babies grow, the time spent feeding and changing nappies reduces and other activities (such as playing) become more important. The table below gives a breakdown of time spent on different activities in the first year.

However, one of the most interesting survey findings here is the amount of time multiple mothers are alone, with half of mothers (48%) spending less than an hour talking to another adult.

As mentioned in the earlier section on postnatal depression, lack of sleep is a common problem for multiple parents. Exhaustion and fatigue are recurring issues, with 45% of mothers sleeping less than 5 hours over a 24 hour period. Only 14% have six or more hours sleep. (It should be noted that this is total number of hours and for many mothers this sleep is broken by regular night-waking, feeding and settling babies).

In the following section, we expand on the help available to mothers of multiples, which might improve their prospects of getting more sleep.

Q16. Time spent on different activities EACH DAY during the first year

| | Under 1 hr | 1-2 hrs | 2-3 hrs | 3-4 hrs | 4-5 hrs | 5-6 hrs | 6 hrs+ |
|--|------------|---------|---------|---------|---------|---------|--------|
| Changing nappies | 18.4% | 49.9% | 20.0% | 6.8% | 2.7% | 1.4% | 0.8% |
| Feeding | 0.5% | 3.0% | 16.9% | 21.8% | 20.7% | 20.0% | 17.3% |
| Bathing/cleaning/dressing babies | 14.9% | 52.3% | 23.3% | 6.7% | 1.8% | 0.7% | 0.2% |
| Shopping | 71.6% | 21.8% | 5.1% | 1.0% | 0.2% | 0.1% | 0.2% |
| Visits to health practitioners/clinics | 79.3% | 16.8% | 2.6% | 0.9% | 0.1% | 0.1% | 0.2% |
| Playing | 13.1% | 30.6% | 30.1% | 15.0% | 5.9% | 3.0% | 2.3% |
| Talking to/meeting other adults | 47.7% | 37.1% | 10.0% | 3.5% | 0.8% | 0.6% | 0.3% |
| Sleeping yourself (in 24 hr period) | 1.0% | 1.4% | 4.0% | 10.8% | 28.3% | 40.5% | 14.2% |

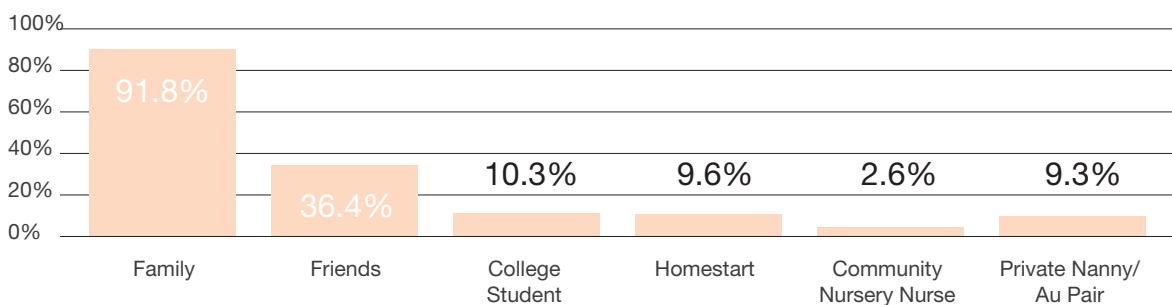
One of the most interesting survey findings here is the amount of time multiple mothers are alone, with half of mothers (48%) spending less than an hour talking to another adult.

7

Help

An extra pair of hands is highly valued by multiple mothers. The most common source of help in the first six months is family members (91%), followed by friends (36%), college students (10%), Homestart (9.6%), private nanny/au pair (9.3%) and, for a few families, a community nursery nurse (2.6%).

Q17. Percentage of respondents who received help caring for their babies from the following sources in the first 6 months



Comments in this section suggest that ‘family’ often means just ‘partner’, and frequently only for the two weeks paternity leave. Mothers who rely on regular help from their family and friends consider themselves one of the ‘lucky few’. Unfortunately, not all mothers had people around who could help them: “I think some form of respite care should be available to multiple mums, especially those with no local family support network to help out”.

Homestart (an organisation which provides support and friendship to families, irrespective of whether they have multiples or not) is described as a ‘godsend’ for many respondents and can provide a great source of support. However, some mothers live outside Homestart boundaries, whilst other respondents commented that it takes a while to administer the paperwork (filling out forms, interviewing mothers to work out their needs and finding suitable volunteers) before help becomes available. By this time, some respondents no longer need the help. If possible, Tamba recommends mothers should begin arranging for Homestart help while they are still pregnant.

College students looking for hands-on practical experience of babies can also be helpful, although some respondents said they had been told “they are no longer able to send them out to homes because of insurance”. College students are also only available at specific times during the year, which coincide with their practical work-experience terms.

Recognising the additional demands that multiple births make on new mothers, Tamba recommends that fathers of multiples should be given 2 weeks paid paternity leave per child, not per birth (i.e. 4 weeks paternity leave for twins and 6 weeks for triplets).

Additionally, the Government should take urgent action to improve and increase access to sources of practical help for new mothers of multiples. Options include grants to hire mothers help, in accordance with the particular needs of mothers of multiples, and council-organised respite care.

8

Membership of TAMBA/Twins Clubs

68% of respondents are members of Tamba, which was praised for providing information about multiple-pregnancy-related complications, such as TTTS.

In particular the TAMBA internet forums were highly valued: “I have had fantastic online support from the TAMBA messageboards!” and “the Tamba message board was the greatest comfort at this time [coping with PND] as I felt like the worst mother in the world - until I read that lots of twin mums have similar experiences”.

Half of respondents (49%) belong to a local Twins Club, which is extremely important for some mothers in coping with PND. One respondent commented “only [the] support of my local twins club and other twin mums got me through”. As mentioned in Section 2, twins clubs also play a vital role in multiple-specific parent education classes during pregnancy.

9

Policy Recommendations

Continuity and expertise in prenatal care for multiples

- All expectant mothers of multiples should be seen within six weeks of identification of multiple pregnancy by a designated consultant with experience of multiples.
- All Trusts to provide access to parent education class for mothers of multiples within six weeks of identification of a multiple pregnancy with reference to the ‘Good Practice Principles’ identified by TAMBA in Section 2.

Good nutrition = better outcomes

- Midwives to offer ‘tailored’ nutritional advice to mothers of multiples during early antenatal appointments to ensure better outcomes. In the case of pregnancy-related complications mothers should have access to a hospital dietician.
- Hospitals to ensure sufficient food portions for expectant mothers of multiples and nursing mothers.
- Each hospital to have a dedicated midwife on maternity wards with experience of supporting women with breastfeeding multiples.

Keeping mothers and babies together

- More investment in special care units so that mothers can be accommodated at their local hospital. Priority should be given to mothers of multiples, so that mothers and babies are not separated after birth.
- Transitional wards to be built near the special care units so that mothers and babies can stay together.

Supporting Parents of Multiples with Postnatal Depression (PND)

- All parents of multiples to be offered home visits by trained community midwives and health to ensure early identification of PND and continuing support where needed.
- Health professionals should be made aware that PND can be triggered when children are ill (especially colic). Doctors and midwives should check if mothers are coping (mentally) while also offering medical advice to children.
- Funding to be made available (£50,000) to enable the TAMBA helpline to be staffed 24 hours a day, seven days a week.

Supporting Families with Multiple Births

- Fathers of multiples should be given 2 weeks paid paternity leave per child, not per birth (i.e. 4 weeks paternity leave for twins and 6 weeks for triplets).
- Access should be improved to sources of practical help for new mothers of multiples, including grants to hire mothers help, in accordance with the particular needs of mothers of multiples, and council-organised respite care.