



An evaluation of the Care of the Next Infant (CONI) programme

Final report (March 2021)

"After our loss we never thought we would have peace of mind with another child, but we do. It is unbelievable. The worries and fears were taken away"



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Contents

1. Executive summary.....	1
1.1. Key findings.....	1
1.2. Key recommendations	1
2. Introduction	2
2.1. The Care of the Next Infant (CONI) programme	2
2.2. Desired outcomes.....	3
2.3. The programme during COVID	3
3. Evaluation method.....	4
4. Feedback on the different elements of the CONI programme.....	5
4.1. Usage	5
4.2. Helpfulness.....	5
5. The practical impact of the CONI programme	7
5.1. Safe sleeping	7
5.2. Responding to baby's emotional needs	8
6. The emotional impact of the CONI programme.....	8
6.1. Reduced anxiety	8
6.2. Increased confidence	9
6.3. Reduced isolation	10
6.4. Overall satisfaction.....	10
7. Feedback for improving the programme	11
7.1. Awareness amongst other professionals	11
7.2. Health visitor knowledge of monitors.....	12
7.3. Difficulties using the monitors.....	12
8. Conclusions and recommendations.....	13

1. Executive summary

The Lullaby Trust's Care of the Next Infant (CONI) programme provides emotional and practical support to bereaved families during pregnancy and throughout the early months of their new baby's life. It aims to increase parental confidence in looking after their baby, their awareness of their baby's needs, and improve their mental health and wellbeing by reducing anxiety, stress and isolation.

Fiveways was commissioned to conduct an evaluation to determine the programme's success in delivering these outcomes and how it might improve its future effectiveness. The evaluation involved a review of data from CONI feedback surveys, in-depth telephone interviews with 12 parents, and discussion with the CONI programme management team.

1.1. Key findings

- The CONI programme is considered by parents to be an overwhelmingly positive experience both practically and emotionally. Of 70 survey respondents, 79% described the programme as "very helpful" and 16% as "helpful". No-one found it to be unhelpful.
- It is evident from qualitative responses that support from the CONI programme has built parental confidence. 89% of parents (59) agreed with the statement "I feel better able to cope with anxiety about my baby's health because of the support I received from CONI" – only one parent disagreed.
- 70% of parents (57) agreed with the statement "I feel less isolated as a result of the support I received from CONI" with 7% disagreeing.
- Parents on the CONI programme receive more regular visits from a health visitor and these are central to the achievement of the project's outcomes. Qualitative responses reveal that increased contact with health visitors provides parents with both practical support (e.g. regular weighing and improved access to health services) and emotional support (having someone to talk to, and the reassurance that baby is progressing well).
- The programme has managed to maintain a high level of service despite the challenges of the first COVID lockdown, which meant home health visitor visits were not possible and key programme staff were deployed elsewhere.

1.2. Key recommendations

For those parents who did have feedback for improvement, comments focussed on raising awareness of the programme amongst other professionals, increasing health visitors' knowledge about monitors, and practical difficulties of using the monitors. Our recommendations for the CONI programme are as follows:

- Promote the emotional benefits of the programme as well as the practical features
- Enable parents to easily access information on monitors and share their experiences
- Support parents to respond in situations where professionals are unaware of CONI
- When it comes to raising awareness of the CONI programme, focus on midwives.

2. Introduction

2.1. The Care of the Next Infant (CONI) programme

Families who have experienced the sudden and unexpected death of a baby or young child are often very anxious when they have another baby.

The Lullaby Trust's Care of Next Infant (CONI) programme provides emotional and practical support to bereaved families during pregnancy and throughout the early months of their new baby's life, allowing them to enjoy this special time.

Working with midwives, doctors (GPs), health visitors/health professionals and paediatricians CONI aims to give parents confidence in looking after their baby.

Although what is on offer can vary slightly from location to location, the following support is available to CONI families:

- Increased contact with a health visitor or health professional
- The loan of, and support to use a movement monitor which picks up movements as their baby breathes. An alarm will ring if movements stop for longer than 20 seconds.
- Basic life support training
- A symptom diary to record their baby's health
- A Baby Check App that helps parents decide if their baby needs medical help.
- A detailed weight chart to monitor their baby's growth and help them to see changes that may mean their baby should be seen by a doctor
- A handy room thermometer to help them keep the room where their baby sleeps at a safe temperature, plus tips on bedding and clothing.
- The CONI healthcare passport - A sheet that goes inside their baby's "Red Book" so that if they are worried that their baby is unwell, they can be seen quickly by the right person.

2.2. Desired outcomes

The CONI programme aims to deliver the following outcomes for parents and professionals.

Value created	Key question	Outcome indicators
Immediate value	What happened? What is people's experience?	<ul style="list-style-type: none">• Uptake of different support options• High levels of satisfaction with delivery
Potential value	What difference has the service made to people's knowledge, feelings and attitudes?	<ul style="list-style-type: none">• Increased awareness of baby's needs• Increased confidence in looking after baby• Increased feeling that they can cope• More relaxed when baby sleeps
Applied value	What difference has the service made to what people do?	<ul style="list-style-type: none">• Reduced smoking behaviours• Safer sleeping behaviours• Increased breastfeeding behaviours
Realised value	What difference have those actions made to achieving the project's desired objectives?	<ul style="list-style-type: none">• Improved mental health and wellbeing [e.g. reduced anxiety, stress, isolation, feelings of inadequacy]• Enjoyment of being with baby
Transformative value	What difference has been made to the wider context?	<ul style="list-style-type: none">• Professionals more able/confident to support more at-risk families

2.3. The programme during COVID

As with many activities the CONI service was severely affected by the COVID pandemic – and particularly the first national lockdown between the end of March and July 2020.

During that time CONI co-ordinators (who are also registered nurses) were re-deployed to support the NHS's response to COVID, so their CONI work passed to health visitors less experienced in delivering the programme. In turn, those health visitors covering the work of re-deployed colleagues were under great pressure – caused by the pandemic itself (e.g. self-isolating or becoming ill themselves), workload, not feeling prepared or confident to deliver CONI (even in normal times there can be lengthy gaps between supporting CONI families), and not having the time to update themselves on the programme (for example, on how to use the movement monitors).

Even in normal times, delivering the CONI support is on top of a health visitor's normal work (they do not have extra hours to deliver it). So it is understandable if, during such a difficult time, mandated health visiting work took priority.

The lockdown also resulted in logistical problems. Health visitors were unable to visit families and meet them face to face – instead, the service was delivered remotely. Health

visitors also found it difficult to access office and stores of equipment (e.g. movement monitors).

The programme adapted quickly to these challenges. “Bitesize” information presentations were developed to support co-ordinators deliver the programme. They were able to signpost families to the videos and then have conversations about them.

Update/Q&A sessions for health visitors were replaced by Zoom sessions and email newsletters (although if a co-ordinator had been re-deployed, they may not have received and shared the emails).

Leaflets for parents and other resources were provided centrally. Stock was kept with Lullaby Trust staff and at a distribution centre.

From the programme’s perspective it is felt that CONI families during this period did not get the same level of support as they might have done outside of a pandemic. However, a family may not have anything to compare it to, and even those who had received the support previously may not have required the same level of support.

After July 2020, during the tiered lockdowns and second national lockdown most CONI co-ordinators were not re-deployed.

3. Evaluation method

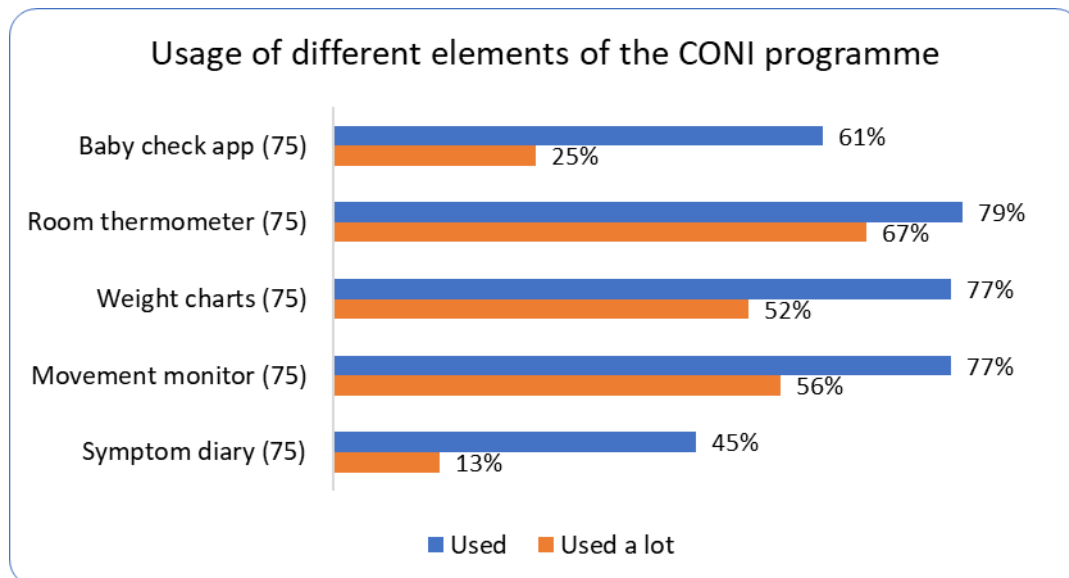
The evaluation of the CONI service involved the following:

- A review of data collected from CONI feedback surveys in 2020 (from 75 parents) and comments from surveys completed since June 2019.
- In-depth telephone interviews with 12 parents who had experienced the CONI programme between 2019 and 2021. Parents were thanked for their time with a sleep sack donated in kind by Halo, supporters of The Lullaby Trust.
- Discussion with the CONI programme management team at the Lullaby Trust.

4. Feedback on the different elements of the CONI programme

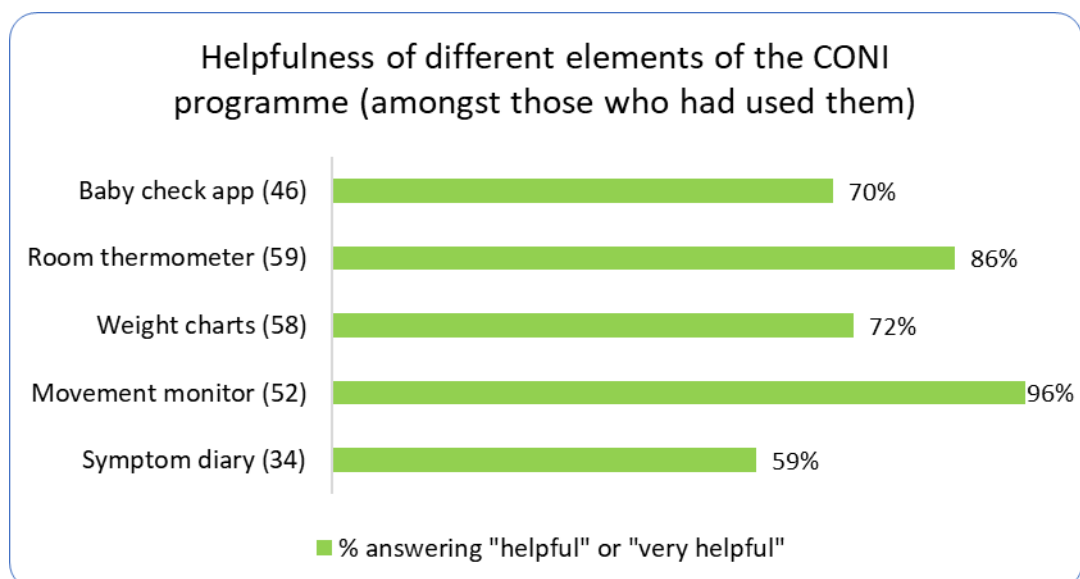
4.1. Usage

The most used elements of the CONI programme are the room thermometers, weight charts and movement monitors. Usage, and especially frequent usage, is lower when considering the symptom diaries and the baby check app.



4.2. Helpfulness

The most helpful element amongst parents who had used them was the movement monitor with all but two of the 52 parents who had used one describing it as "helpful" (8%) or "very helpful" (88%). Those elements with lower frequent usage (the baby check and the symptom diary) were still found to be helpful by the majority of those that used them.



The feedback from the interviews supports the survey results in that most research participants had used several of the elements on offer and found them useful. For some, the extent and range of the support provided by CONI came as a welcome surprise.

"I just thought he might get more checks on the day he was born. But we have monitor, weighing, a symptom diary, and a pass for hospital. It is really reassuring – amazing. More than I thought it would be." (Interview 5)

"I didn't realise how much more there was. Every base was covered. We weren't expecting extra level of help from the health visitor. That personal support was really important." (Interview 1)

When asked about the most helpful elements of the programme, interviewees tended to focus on three themes: the monitor, regular contact with a health visitor – especially for weighing, and improved access to health services.

The monitor

The movement monitors were mentioned by all the parents and are a highly valued element of support. *"I only agreed to go on CONI for the apnoea monitor you get." (Interview 3).* We will explore below the specific impact the monitors have on parental anxiety below (6.1), but most parents clearly found them helpful, describing them as "a life saver", "a lifeline", and "absolutely invaluable".

"The monitor was very helpful. I don't think I could have slept a good night's sleep without it." (Survey)

Increased visits from a health visitor

Parents on the CONI programme benefit from having appreciate having frequent visits from the health visitor. We will see below the emotional benefits this increased contact has, but the practical benefits are also clearly appreciated. For example, several parents welcomed the extra layer of observation provided by having their baby weighed more regularly – *"reassuring me he is thriving."* (Interview 4). The bespoke weight charts play a big part here too – *"to see a chart with such small increments was really useful"* (Interview 12).

In addition, some mentioned the health visitor's support to arrange other health appointments for them.

"The health visitor visited every week, I was able to phone her at any time, she phoned the GP to make appointments, and made sure my notes indicated we were on CONI." (Interview 1)

"My health visitor liaised with my doctor so we could bypass the receptionist and ask the doctor to ring." (Interview 4)

The healthcare passport

The healthcare passport that enables parents to access specialists promptly was also highly valued – not just for the access but because it meant they did not have to tell their story again when contacting services.

"It was good to be able to say, 'I am on the CONI scheme' rather than 'my child has died'." (Interview 3)

"In the last experience, we were in hospital and doctors were not taking things seriously, that was a big thing for us. The passport gave us peace of mind when we did have to pop to the hospital, we were seen a lot quicker. It worked." (Interview 6)

"I could contact the paediatrician directly. They came round twice, and I could build up trust and rapport with them which was important. Having that 'in' was great for reassuring me." (Interview 9)

5. The practical impact of the CONI programme

5.1. Safe sleeping

In the feedback survey 72 parents answered the question "where did your baby wake up this morning?" 63 (88%) answered "in their own cot or sleep place", 8 (11%) had woken up in the respondent's bed.

All the parents interviewed mentioned receiving safe sleeping advice as part of the CONI programme. For most the advice confirmed they were doing the right thing and that they did not need to change anything.

"They give clear, trusted advice - nothing that isn't common sense, but it pushes awareness, not to have your baby in bed with you." (Interview 7)

Some also felt they had been also doing the right thing with their child who had died, "we did all of that first time round." (Interview 5)

"We were aware, we had the knowledge – but the baby had managed to roll over onto their face. [The safe sleeping advice] had not prevented it happening." (Interview 12)

However some parents mentioned aspects of "new" information that they gained from CONI that they did not know before including dummies may help to reduce risk of SIDS, and the importance of room temperature and clothing to avoid overheating.

5.2. Responding to baby's emotional needs

The programme seeks to support parents to be more aware of their baby's emotions and needs. This aspect of the service was not always well recalled. Some parents interviewed did not remember it coming up, but for others it had clearly been helpful and the extra visits from the health visitor had provided the opportunity for this information and support to be provided.

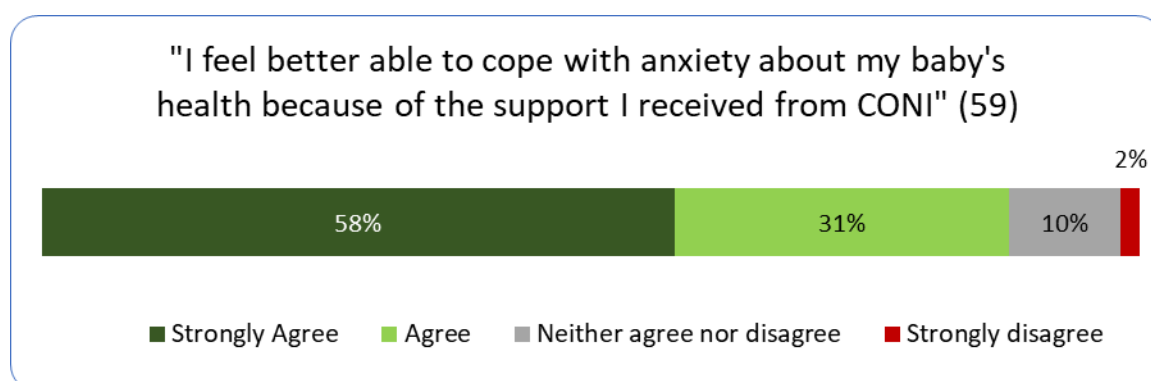
"The health visitor went through the four stages of emotions, so when baby wants more interaction or less. I felt better prepared, I knew the cues which made things simpler, I would know she [the baby] was tired before anyone else." (Interview 8)

"My baby had really bad colic – the health visitor taught me different ways to hold her and tummy massage to calm her down and they worked really well." (Interview 10)

6. The emotional impact of the CONI programme

6.1. Reduced anxiety

89% of parents (59) agreed with the statement "I feel better able to cope with anxiety about my baby's health because of the support I received from CONI" – only one parent disagreed.



The qualitative feedback supports the survey findings. All parents interviewed mentioned how the various elements of the CONI programme had reduced their anxiety and helped them cope.

"I can actually sleep knowing baby is wearing something that is going to alarm me should I need to get up. We weren't sleeping, we were sitting up all night. We have learnt to trust the monitor. We have peace of mind, we can phone the health visitor about things that may have a rational explanation and we may know what to do - but we are in an irrational state of mind – the health visitor calms me down, talks me through it and texts me afterwards to see if we are okay." (Interview 5)

"I slept a lot better – the monitor calmed us down. We would have been nervous a lot of the time, and [our] anxiety would have been really bad." (Interview 10)

"It has made having a second child smoother – you don't feel alone, the support is there. It doesn't feel as stress inducing." (Interview 7)

"They gave me sanity, they helped me cope. They put me back on the right track." (Interview 11)

The monitor can also raise anxiety

Paradoxically, for a few parents, the monitor could increase their anxiety, at least in the short term before they become accustomed to it.

"The monitor did make me more anxious, so I stopped using it after a few weeks" (Survey)

"The alarm helped, but it could also increase my anxiety if there was a long pause between clicks, but I would have been anxious anyway." (Interview 1)

6.2. Increased confidence

Parents interviewed often mentioned that as well as reducing their anxiety, the support from the CONI programme built their confidence. Part of this was a sense that the support had gradually made them more confident that, despite having experienced loss, it was not likely to happen again. This, in turn, led some to feel more confident in themselves as parents.

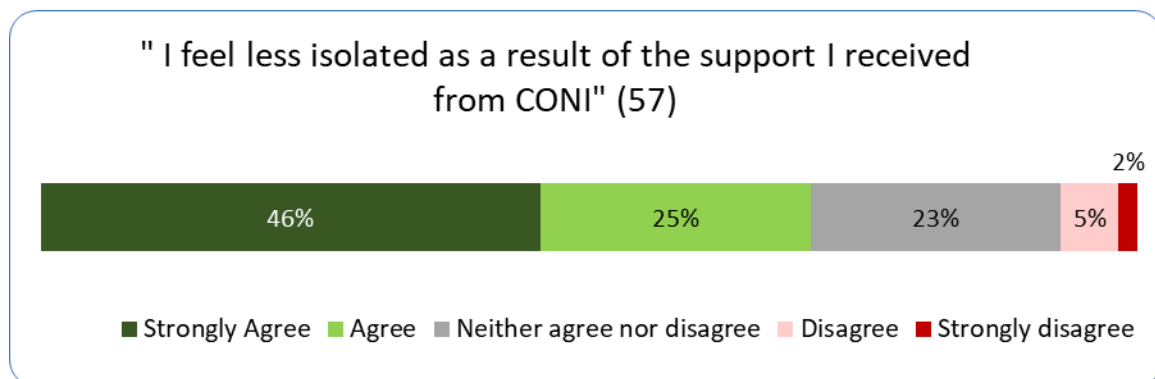
"They have helped me to not put that pressure on myself and re-train my brain that my child is actually okay. I had to think I can leave him in a room on his own and he would be okay. They showed me he was thriving, developing, hitting the milestones – they gave me confidence he is doing well. They made me feel 'I can do this.'" (Interview 11)

"They gave us breathing room early on and reduced our anxiety a lot, and we grew in confidence so we could get into the swing of parenting. We are really grateful that it exists." (Interview 1)

"When my eldest passed away we thought everyone was against us, the world is a nasty place. When you have this scheme and people are so amazing, you have so much help and support, it gives you the positivity you need back in your life – and confidence that I can do this, I can look after him, I can be a Mum again" (Interview 5)

6.3. Reduced isolation

70% of parents (57) agreed with the statement "I feel less isolated as a result of the support I received from CONI" with 7% disagreeing.



Having someone to talk to

The qualitative interviews revealed that the emotional support element of the CONI programme is very important to parents. We have seen above the practical benefits that accrue from CONI parents having more frequent visits from a health visitor, however the emotional and psychological benefits of building a relationship with the health visitor over several visits become more important for many parents.

The comfort, solace and reassurance they gain from "having someone to talk to" is valued just as highly as the more practical elements of the programme (monitors, weighing and service access) explored above. *"I was very relieved to have someone to talk to and share problems."* (Interview 2). Potentially this aspect of the programme could be emphasised more in its promotion to parents.

6.4. Overall satisfaction

The feedback survey reveals a high level of satisfaction with the programme. Of 70 respondents, 79% described the programme as "very helpful" and 16% as "helpful". No-one found it to be unhelpful.

This very positive feedback was also evident in the qualitative responses, with the programme being described regularly as "brilliant", "fantastic" or "amazing."

"It's an amazing service, everyone who has suffered a baby death should use it."
(Interview 9)

"I feel lucky to have had the support when we were going through absolute hell – I feel blessed. It is invaluable to any family going through that heartache." (Interview 11)

"I can never thank them enough – phenomenal, the best programme by far." (Interview 5)

"I feel like my baby wouldn't be here today if it wasn't for the CONI programme." (Survey)

7. Feedback for improving the programme

As we have seen above, the CONI programme is considered by parents to be an overwhelmingly positive experience both practically and emotionally. When asked about what the programme could improve on, some parents replied saying that it “couldn’t be faulted.”

For those parents who did have feedback for improvement, comments fell under three main themes: the awareness of the CONI programme amongst other professionals, the level of the health visitor’s knowledge about monitors, and practical difficulties of using the monitors.

7.1. Awareness amongst other professionals

The fact that some professionals in other services were not aware of the CONI programme was a common theme in the feedback. As noted above, improved access to services postnatally is a highly valued element of the programme – so when professionals are not aware that a parent and child are on the programme that can cause upset. A range of professionals – including GPs, those working at GP practices, midwives and A&E staff were mentioned in this regard.

“We went to hospital A&E, but they didn’t have any idea about CONI.” (Interview 1)

“The GP surgery had no idea what it was. Every time I phoned, I had to explain what it was. You are meant to be seen quite soon if you have a concern, but we didn’t get any of that. I would say ‘he’s on the CONI scheme and he is not eating’ – they weren’t aware what it was, they didn’t acknowledge the scheme.” (Interview 3)

When I spoke to midwives and receptionists, they didn’t seem to understand what the CONI scheme was. I had to explain on the phone, E.g. he was jaundice, and I wanted the blood tests quickly – but wasn’t prioritised. When I mentioned CONI there was silence at the other end of the phone.” (Interview 4)

“There needs to be more awareness. It is not known in other professions – some do not have a clue, for example midwives should know. They ask if I have any other children – that is a very difficult conversation to have.” (Interview 11)

Linked to this is a lack of knowledge of the scheme amongst professionals seeing parents antenatally – particularly midwives as they have an important role to play in promoting the programme to families. This was particularly evident in responses to the survey.

“I was not aware of the CONI programme during my pregnancy [so] I didn’t get on the programme until my baby was 6 weeks old when I spoke to my health visitor about my concerns and she referred me, it has been good for us.” (Survey)

“Although midwives etc speak about SIDS a lot during pregnancy they never mentioned the programme, I would like to have known about it during pregnancy.” (Survey)

"Initially the midwife did not explain the scheme clearly and I was worried that someone would be interfering all the time and I would be visited by lots of people. The health visitor and the CONI coordinator were really good at reducing my anxiety and making it feel comfortable." (Survey)

In the interviews, a couple of parents mentioned having to "pester" midwives to be referred to the programme antenatally.

"I had to instigate it, push for it. I kept mentioning it to the midwife. It was stressful during run up that things had not been sorted. We wanted to be ready to go. [CONI] needs to alleviate anxieties in the run up – you are worried you might slip through the net." (Interview 12)

7.2. Health visitor knowledge of monitors

A few parents mentioned that they would have liked their health visitors to have had more knowledge about different monitors. This possible knowledge gap can be explained by the fact that health visitors can go several months without supporting a family on the CONI programme and technologies change quickly. Also, CONI co-ordinators may not have the time to educate and upskill health visitors. We also saw above that one of the impacts of COVID was that less experienced health visitors, under a lot of pressure, were delivering the programme for several months during this period.

"The health visitor had never heard of the owlet sock.¹ I was teaching her things. It would give you an extra bit of confidence if they did know and you could ask them what to do if you had an issue with the monitor." (Interview 7 – possibly affected by COVID)

"The health visitor hadn't done it in a while which made things slower. I had to do research myself which was frustrating as I didn't know how up to date that information was. It took three months for the health visitor to get back to me with which monitors the Lullaby Trust recommends" (Interview 8, pre-COVID)

7.3. Difficulties using the monitors

Several parents mentioned practical difficulties using the movement monitors, such as their size and bulkiness, the wires getting in the way, and the strength of the adhesive tape that attached the wires to the baby. These difficulties were compounded as babies grow and become more mobile. In one case a parent mentioned that these difficulties increased bed sleeping.

"Bed sleeping slipped in because of the difficulty picking up baby and the monitor and going into a chair." (Interview 12)

¹ The owlet sock is an American device and not one of the monitors provided by CONI. Parents do use their own monitors and, in such cases, health visitors are encouraged to encourage parents to refer to the manufacturer's instructions.

8. Conclusions and recommendations

The evaluation has revealed that the CONI programme is highly valued by parents who find it very helpful both practically and emotionally.

The programme is proving successful in delivering several of its desired outcomes, particularly increased parental confidence in looking after baby, increased feeling that parents can cope, increased safer sleeping behaviours and improved parental mental health and wellbeing - such as reduced anxiety, isolation and feelings of inadequacy. Key to delivering these outcomes are the more regular visits from a health visitor that parents on the CONI programme receive.

The programme has also managed to maintain a high level of service despite the challenges of the first COVID lockdown, which meant home visits by health visitors were not possible and key programme staff were re-deployed to support the COVID response.

The evaluation has also raised some points for the programme to consider in order to maintain and improve this positive feedback.

- **Promote the benefits of the programme as well as the features.** Parents experience significant emotional benefits from being on the CONI programme (improved confidence, less isolation, less anxiety). These benefits could be highlighted more when promoting the programme. Current communications tend to focus more on the practical features of the programme (the monitor, the visits, the passport etc).
- **Enable parents to easily access information on monitors and share their experiences.** If it is difficult to make sure health visitors are up to date with the range of monitors available, then it is worth considering how this information can be delivered directly to parents – possibly through a website resource they can easily access. If moderated appropriately, such a resource (e.g. a CONI Facebook page) may also provide an opportunity for parents to support each other with queries, tips for how best to use the monitors, and how to cope with the anxiety they cause for some. Health visitors could then signpost parents to that resource (and use it themselves in conversation with parents).
- **Support parents to respond with situations where professionals are unaware of CONI.** Undoubtedly there is a job at hand to make sure key professional groups are aware of CONI – but this is a significant challenge as there is so much those professionals need to know and they are often working in a pressured environment. An alternative approach would be to ensure parents are aware of the possibility they might encounter an unaware professional and guide them in how best to respond to that situation – for example with a form of words to use, or information they could send or signpost the professional to.

- **When it comes to raising awareness of CONI, focus on midwives.** One way to reduce parental anxiety is to make them feel prepared before birth, perhaps having tried out a monitor. The evaluation has revealed a concern about the knowledge of the scheme amongst a range of professionals and especially midwives. They have a key role to play before and immediately after the birth (health visitors usually pick up the care of the parent 10-14 days after birth), so it is recommended that the Lullaby Trust explore opportunities to support more midwives to effectively engage with the CONI programme.

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