FRIENDS, FAMILIES & TRAVELLERS

SUMMARY REPORT:
GYPSY, ROMA AND TRAVELLER COMMUNITY EXPERIENCES OF INFANT FEEDING, INFORMATION AND SUPPORT SERVICES

gypsy-traveller.org

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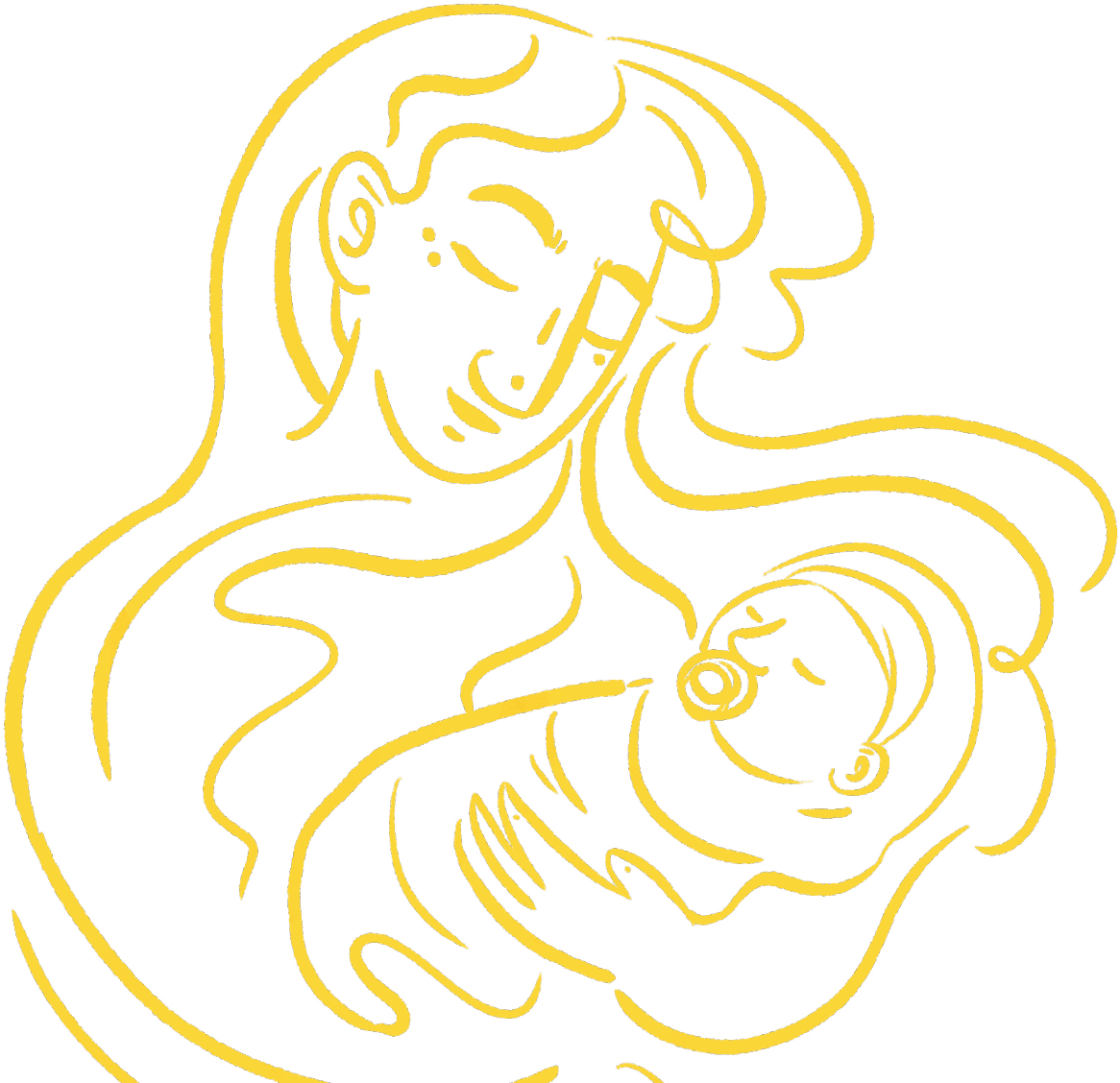

About us

This piece of research was conducted by Friends, Families and Travellers and Roma Support Group, through their work as members of the VCSE Health and Wellbeing Alliance.

Friends, Families and Travellers (FFT) is a leading national charity that seeks to end racism and discrimination against Gypsies, Travellers and Roma and to protect the right to pursue a nomadic way of life. We support individuals and families with the issues that matter most to them, at the same time as working to transform systems and institutions to address the root causes of inequalities faced by Gypsy, Roma and Traveller people. Every year, we support over 1,300 families with issues ranging from health to homelessness, education to financial inclusion and discrimination to employment. Over half of our staff team, volunteers and trustee board are from Gypsy, Roma and Traveller communities.

Roma Support Group (RSG) is a Roma-led charity based in East London, working to improve the quality of life for Roma refugees and migrants by helping them to overcome prejudice, isolation, and vulnerability. Every year, we support around 2,000 Roma people with access to welfare, health services including mental health, education, financial inclusion, campaigning and policy, housing and cultural activities. Every year, about 120 Roma people benefit from one-to-one health advocacy. Since 1998 the RSG has worked with thousands of Roma families, offering them a variety of services, engaging the Roma community in all aspects of running and managing the organisation and promoting an understanding of Roma culture in the UK.

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INTRODUCTION

Gypsy, Roma and Traveller communities are known to face some of the starkest inequalities in healthcare access and outcomes amongst the UK population, including when compared to other minority ethic groups[1]. These inequalities are also reflected in Gypsy, Roma and Traveller experiences of maternal health and care. This piece of research builds upon work conducted by Friends, Families and Travellers (FFT) and Roma Support Group (RSG) which culminated in the publication of our 2023 Guidance on Tackling Maternal Health Inequalities in Gypsy, Roma and Traveller Communities.

This summary report synthesises key findings and recommendations drawn from FFT & RSG's full report on the experiences of Gypsy, Roma and Traveller communities around infant feeding support and early information. The aim of this report is to amplify the voices of Gypsy, Roma and Traveller community members and to improve knowledge and understanding around the needs and experiences of these communities within the health and care system.

It is important to note that not all members of Gypsy, Roma and Traveller communities share the same life experiences. Some individuals will not necessarily experience all, or any, of the barriers outlined in this report. However, by increasing awareness around the experiences of the most marginalised patients, we can begin to create services that are accessible and welcoming to all.

For the complete research findings and recommendations, our research methodology and crucial background information on Gypsy Roma and Traveller communities as well as the infant feeding policy context, please view our full report.

[1] Friends, Families & Travellers (2022) Briefing: Health inequalities experienced by Gypsy, Roma and Traveller communities

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KEY FINDINGS

1. **Cultural norms around infant feeding vary** across different Gypsy, Roma and Traveller communities.

i) Within **Roma communities breastfeeding may be more typical**.

"There is a pressure from the community to breastfeed – because everyone talks about it as being the preferred method, you feel pressure that you should be doing it."

ii) **Formula feeding is more culturally expected among many Romany Gypsy, Irish Traveller and Travelling Showmen families.**

"[breastfeeding is seen as] not what we do [...] not normal..."

iii) Research participants described a degree of **discomfort or stigma around breastfeeding** for some members of these communities.

"The generation below me are more likely to give breastfeeding a go, but before that it was such a taboo. A lot of it goes down to modesty."

iv) **Modesty, privacy, health impact and family/community** were cited by participants across all communities as major factors in infant feeding decision-making and practices.

2. A **lack of culturally pertinent and accessible information and support** on infant feeding was reported by participants, with many parents indicating that services did not feel tailored or suitable for their needs and experiences. This is linked to **literacy and language barriers as well as a lack of cultural competency or awareness around structural issues accessing primary care** for nomadic or migrant families and families who live in insecure accommodation or shared housing.

"I struggled with breastfeeding for both children but I didn't know who to speak to. I needed an interpreter, but I didn't have one."

"I struggle with reading and writing, booking stuff in... I don't think she [health worker] really understands needing help with literacy, she gives me all this paperwork..."

"Would have been good to have resources on how to sterilise with limited water/ power and ways to store milk."

3. **Accommodation and living circumstances** were also highlighted as having a major impact on infant feeding experiences and ability to access services.

"People who are travelling don't have consistent people [care providers], it's just whoever is available – it's hard to learn to trust anyone."

"I couldn't drive or leave home because my c-section scar was infected, I was having a horrible time - but the health visitor wouldn't come to site, so I was stuck. Then I got a call saying 'You've missed appointments so we're going to send social services'. It's like, you can send them down [to the site], but you didn't want to send [a health visitor] down to change my dressing or weigh the baby!"

"We had health visitors visit us on the boat for the first month, then we moved the boat into a different HV jurisdiction, and no one visited after that - we got lost in the system as no one seemed to care about us."

4. Parents described feeling **stigma, pressure and judgement around their feeding choices, both from health professionals and from within their own communities**. Some reported feeling that they 'couldn't win', as they would either face stigma from within their community for choosing to breastfeed, or shame from health professionals if they chose to formula feed.

"Instead of health professionals judging me, my own community did! You can't win."

5. **Messaging from health professionals around infant feeding options was often deemed too rigid or pressurising by participants**. Some participants felt pressured towards exclusive breastfeeding, despite expressing that more flexible strategies such as combination or mixed feeding would be more suitable for their needs and living circumstances. In some cases, rigid 'all or nothing' messaging around breastfeeding put participants off from exploring breastfeeding at all, despite initial interest.

"I remember breastfeeding being pushed on me. I felt very overwhelmed – they were just coming at me and coming at me... I was like no, I'm sick of this, I'll stick with what I've been doing, just leave me alone."

"I didn't know you could do [combination feeding]! I would have tried that if they had said!"

"They just wanted to push me to full breastfeeding, I thought you had to do one or the other."

"I knew I wanted to do mixed feeding, but I always had pushback – didn't have good support in my decision, I always felt pushed to change it [to exclusive breast-feeding]. No one ever asked me why or tried to understand [why I wanted to combina-tion feed]."

6. A **lack of practical and hands-on support** around both breast and formula feeding was noted by many participants. A **lack of culturally relevant peer support opportunities** was also raised.

Mainstream support groups are, simply put, "not for us".

"I knew that they run groups, however this would be intimidating and culturally inappropriate for the majority of Traveller women."

7. The **timing of delivery for information** around infant feeding was raised as an issue; participants pointed to a **need for more information and support before birth**, so that they felt prepared before their baby's arrival.

"I don't think there's nearly enough information before you have the baby – it seems like they wait till you're the most vulnerable you could be [after birth] before they attack you with info."

"We assumed the baby would know what to do! We expected that would be the case and it wasn't! That was a very difficult thing, especially in those first hours."

8. **Experiences of discrimination and prejudice when accessing maternity or infant feeding services** were reported by many participants, resulting for some in a sense of **mistrust or fear** of health professionals or institutions. **Fear of social services** involvement was a notable trend.

"Professionals need to have a better understanding of us – travelling culture... We don't trust authority figures, you'll trust a doctor but then you get that prejudice... we're not an easy trusting culture, it stems from year and year of generational prejudice."

"They don't understand Roma culture."

"The midwife made a discriminatory comment about Travellers leaving rubbish and mess and said she could see I wasn't like this as my home was pristine. It was a home visit in the last few weeks of my pregnancy and I was already feeling vulnerable and tearful. I have never forgotten this experience."

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9. **Concerns were raised by participants around the impact of NHS funding cuts and understaffing**, particularly in terms of the consequences for service delivery and staff wellbeing.

"It's not a reflection on staff, but a reflection on how underfunded they are."

"It's not the fault of the people struggling to do the job under horrendous conditions, a lot of people don't realise where the fault lies – with the government, not the staff."

"Women's choice to breastfeed should be respected and well-funded. I had to pay privately for feeding support."

10. **The cost of living crisis and economic challenges** associated with maternity and infant feeding were a major concern for participants.

i) **Maternity support payments were overwhelmingly considered insufficient**. Moreover, many participants were **unaware of the financial supports available** to support maternity needs.

"It was very difficult to buy everything we needed, even with the maternity grant."

"I didn't know about child tax credits until the midwife who I bumped into at random told me. She was shocked I didn't know. Like 'hasn't your health visitor told you?!' – but I hadn't even had one!"

"No, they didn't tell me anything... You've got to go and find it all yourself online... And you don't want to ask. [My health visitor] didn't even want to come to my site anyway, so I thought if I start asking for help it might make it seem like I'm desperate, or I'm in need, and that might flag something up with social services. I just figured things out on my own, I felt like if I asked her... I mean, she was looking at me funny anyway."

ii) The **cost of formula and feeding equipment** was raised as a major issue.

iii) Many participants felt it was 'better' or 'safer' for babies to be fed more expensive formulas. **All formulas must meet regulatory requirements governing composition and there are no proven benefits of choosing a more expensive milk**.

"I just got the most expensive [formula] as I thought price = quality."

iv) **Literacy barriers** mean that some parents rely on verbal instructions from family or friends to prepare formula – those who lack confidence around doing so correctly **may rely on more expensive pre-prepared liquid formula** to avoid mistakes in preparation. More professional support and instruction should be provided around formula feeding, as well as breastfeeding

11. **Worry and shame around infant feeding** was consistently linked to poor wellbeing and **negative perinatal mental health experiences**. Stigma around mental illness and fear of state institutions/social services intervention were major barriers to accessing mental health support.

"There needs to be more awareness and information about mental health. A lot of Travellers are only just in last 5 years getting to understand mental health as a thing. They wouldn't get help because it was embarrassing and really taboo in our culture."

"I was given a questionnaire about mental health stuff – tick if you felt this or that – I ticked no, because I was worried what they would say or think. My sister-in-law had postpartum but was too scared to say it in case they thought she couldn't look after the baby."

"You can see why women get down after having them [babies]... you're scared you're going to lose your baby - you've got that threat that someone's going to take them off you. They've got that power over you, at the end of the day."

"They never explained what can happen, I didn't know what was normal."

12. This project was unusual in its inclusion of Gypsy, Roma and Traveller **fathers' and male partners' perspectives on infant feeding**. These participants shared their experiences and their views on roles and expectations for men in early stages of parenting:

i) **In some communities, men are traditionally expected to take a secondary role in early stages of childcare. In some maternity contexts, it might not be seen as culturally appropriate for men to be present** (e.g. during childbirth).

"It's not seen as a macho thing, not a man's thing to do... a lot of people won't ask questions, they feel too awkward, like it's a shameful thing."

"I would always leave the room for women's conversations, they don't want me there!"

"I knew whatever questions I had I could have the conversation with my wife afterward. There were things the professionals would talk about that would make me uncomfortable."

"The [Roma] community is still quite conservative – this is seen as the role the mother should have."

ii) These traditions are **not universally observed**, and many participants noted **a generational shift** toward young men being much more involved in infant feeding and early parenting.

"It's not standard for Irish Travellers for men to be involved [with feeding]. I help, and my brother does with his child, but my father never really helped – it's changing as time goes on."

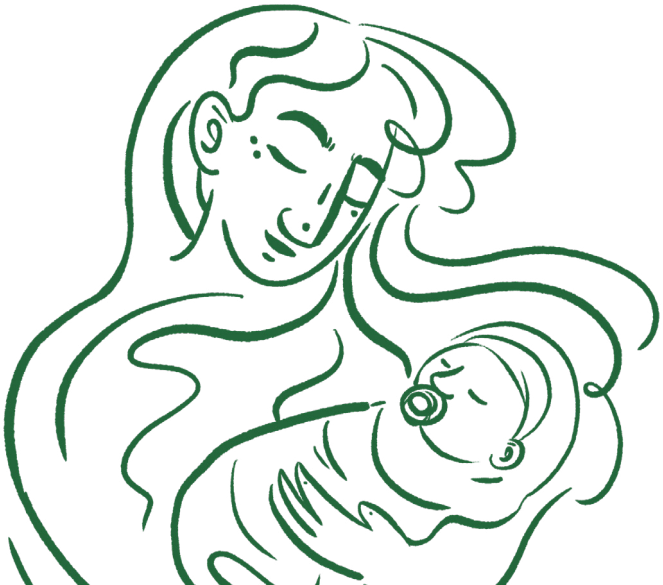
"With my extended family, [men] would get involved more when it comes to solid food, not so much in the breastfeeding period. Even if that includes formula, families aren't so involved. Personally, I was quite a lot, and I can see it changing – others are starting to do it too."

iii) However, participants also expressed concern that **health professionals from outside their community may sometimes misinterpret these cultural norms as a lack of engagement** or interest in the wellbeing of their child or partner.

iv) Participants expressed a **need for tailored information and support around infant feeding for fathers and male partners**. Good practice suggestions for professionals included **initially asking fathers and male partners how involved they would like to be in infant feeding discussions**, without making assumptions about his parenting if he chooses not to be present for certain conversations.

"No [health professionals] involved me [in infant feeding discussions]. Yes, I would have liked them to – not details necessarily, but general things to have some idea! Practical advice, how to support my wife – I think there should be an option maybe. With communities being more or less conservative or traditional and so on, not wanting to be involved should be respected - but it should still be offered! Like if they asked at the start."

"There's space for maybe a leaflet for fathers, to help support and teach them. I would have taken that away and had a look."



KEY FINDINGS

1. **Maternity and infant feeding service providers should engage directly with members of Gypsy, Roma and Traveller communities to assess access needs, and adjust services accordingly.** This process is best facilitated locally by collaboration with organisations or individuals who have existing relationships of trust with communities.

    - Services should be designed to accommodate for needs relating to literacy, language and digital barriers, accommodation-related challenges, as well as cultural norms and expectations common among Gypsy, Roma and Traveller communities. This is especially relevant for registration, booking and contact systems, which should be made as flexible and accessible as possible.

    - Culturally relevant peer support systems and opportunities should be created within infant feeding services for Gypsy, Roma and Traveller communities.

    - Members of Gypsy, Roma and Traveller communities should see themselves represented in the maternity and infant feeding workforce; NHS England should promote recruitment and training opportunities for community members.

    - Where possible, service providers should work with health mediators or community advocates from within Gypsy, Roma and Traveller communities. Ideally, this mediator would be able to provide language support in the service user's first language.

2. **Gypsy, Roma and Traveller cultural competency and inclusive services training is recommended for all maternity and infant feeding service providers. Training services can be found via the Cultural Awareness Hub, which links to training offerings from Friends, Families & Travellers and Roma Support Group, among others**. Relevant training topics for infant feeding and maternity services include

    - Cultural norms and expectations around infant feeding.

    - Practical issues relating to infant feeding while living in culturally pertinent accommodation or insecure housing.

    - Effectively approaching culturally sensitive topics like gendered/sexual health issues and mental health (among others).

    - Cultural expectations around the role of father figures in some traditional Gypsy, Roma and Traveller families.

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3. **Culturally relevant and accessible infant feeding information resources should be provided to maternity and infant feeding service users.**
Where these are not currently available, steps should be taken to fund their development. One excellent example of culturally relevant infant feeding information materials was created by Ireland-based Pavee Point Traveller and Roma Centre's maternal health initiative, Pavee Mothers. Developed by and for Irish Traveller women, this took the form of a website and printed information pack, as well as a text message campaign.

4. Infant feeding policy and support services must respect and support individual infant feeding choices. **Effective, culturally pertinent and accessible support and advice should be available to all families, regardless of which feeding method they choose (including breastfeeding, formula feeding and combination feeding methods).**

5. Suitable funding is critical to the delivery of safe, effective maternity and infant feeding services. **Underfunding of maternity and infant feeding services must be viewed as an urgent political and economic priority**.

Budgets for maternity and infant feeding should be reviewed and increased in accordance with the Ockenden Reports' Immediate and Essential Actions and the latest Health and Social Care Committee report on the Safety of maternity services in England, as a minimum starting point.

- **Commission and sustainably fund universal, accessible, confidential infant feeding support** delivered by specialist/lead midwives, health visitors and suitably qualified breastfeeding specialists, recognising the role of charitable organisations and community groups and their strong links with communities.
- Ensure that **health visiting services** are properly funded and the number of health visitors increased to ensure consistent timely nutritional support for all families to support good maternal and infant mental and physical health.
- Ensure there are accessible and culturally competent **children's centres or family hubs**, disproportionately located in areas of disadvantage, offering joined-up universal services from pregnancy onwards, that include peer support.

6. Awareness among maternity service users around economic, social and psychological support available to families must be improved:

- Broader help and advice services should be integrated into healthcare settings. This could be delivered via a social prescribing system, and/or following a health-justice partnership model, which links new or pregnant parents with advice services through their midwife, enabling them to access benefit entitlements and exercise their rights.

- Migrant parents who may not be familiar with NHS care pathways should be **advised on their NHS entitlements and typical maternity care pathways on first contact with services**.

- **Parents should be advised on what support is available to them as standard practice**, to eliminate the need to ask for help or disclose a problem. Reluctance to do so is often associated with a fear of expressing vulnerability and/or a fear of intervention by social services.

7. Financial supports for families must be improved:

- **Sure Start Maternity Grant** should be uprated in line with inflation and eligibility expanded to second and subsequent children.

- **Healthy Start** should be uprated in line with inflation. Eligibility criteria should also be expanded to include those with No Recourse to Public Funds, in order to reach some of society's most vulnerable families.

- The basic rate of **Statutory Maternity Pay** and **Maternity Allowance** should be **raised to at least the level of National Minimum Wage**.

- The current **8 week qualifying period for Statutory Maternity Pay should be extended** to cover 12 weeks' earnings for those with variable hours so that parents on casual contracts are not disadvantaged.

- The policy anomaly that treats Maternity Allowance as deductible from Universal Credit should be corrected and **Maternity Allowance treated the same as Statutory Maternity Pay under Universal Credit rules**.

- **Administrative barriers to maternity payments** (including both the maternity grant and the additional payments to pregnant women, babies and children under 3), such as the need for a separate application form, **should be removed and payments made automatically after notification of pregnancy**.

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8. Measures must be taken to address the surging costs of infant formula:

- Infant formula should be **recognised as an essential product for which there is no alternative** and be treated in the same way as other essentials such as energy or medicine.

- **Pricing controls and caps** should be explored as a matter of urgency by Government alongside establishing a taskforce to evaluate the feasibility of **commissioning a nationally or locally commissioned first infant formula milk**.

- The Department of Health and Social Care should change its guidance to clarify that retailers are permitted to **allow customers to buy formula with loyalty points, gift cards or vouchers**.

- **Healthy Start Vouchers should be increased so that as a bare minimum they cover the weekly cost of formula feeding**, however this needs to go hand in hand with longer term systemic change to secure access to an affordable product.

- **Clear public health information** must be available in all locations where formula is purchased or advice sought that **all first formulas must comply with regulations governing composition, are nutritionally adequate and comparable, and there are no established health benefits to babies of buying more expensive products**. There is no need for families to buy more expensive infant formulas.

9. Perinatal mental health support services must be strengthened, suitably funded, and delivered in a culturally sensitive manner.

- Service providers should be aware when supporting members of Gypsy, Roma and Traveller communities that there may be a **reluctance to seek help with mental health issues due to cultural taboos and mistrust of healthcare/state institutions**. This can also contribute to a **lack of awareness about perinatal mental health issues and symptoms**.

- These barriers can also contribute to a **lack of awareness around what mental health services are available**. It is therefore important to **emphasise the availability of these services before need for them is expressed**.

10. Decisions made by service providers around the involvement of social services should be handled with great care and sensitivity, as well as an understanding of the distress and harm to families that can be caused by unnecessary referrals.

- Any referral to Children's Services should be made using recognised risk criteria.
- Except in exceptional circumstances, where disclosure may carry the risk of acute harm, any potential referral should be discussed first with the person or family concerned, and their insight and opinion on the referral should be sought.

11. Service providers should be aware of cultural expectations about the role of father figures in traditional Gypsy, Roma and Traveller families.

- Adherence to more traditional expectations around male presence in certain maternity contexts should not be misinterpreted as a lack of interest or engagement on the part of fathers or partners.
- Opportunities should be provided for fathers and male partners to engage in maternity and infant feeding support should they wish to, although the choice not to engage directly should also be respected and not interpreted as a lack of interest in the wellbeing of their child or partner.

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Contact Details:

Address
Friends, Families and Travellers
Community Base
113 Queens Road
Brighton
BN1 3XG

Telephone 01273 234 777

Email fft@gypsy-traveller.org

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