The PATHFINDER Study:

Exploring informal caring Practices And supporT mecHanisms For ethnIc miNority isolateD carERs

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Executive Summary

Why the study was conducted

Across the UK, approximately 5.7 million people provide unpaid care for family members, friends and community members living with long-term illness, disability, or age-related needs. However, significant inequalities exist in access to support, particularly for carers from ethnic minority communities. [1][2][3]

Carers from Somali, Gypsy and Traveller communities often face additional barriers when accessing health and social care services. These include low awareness of available support, language barriers, cultural expectations surrounding family caregiving, geographic isolation, and a lack of culturally appropriate services. [4][5]

Despite these challenges, the lived experiences of carers from these communities remain under-represented in research, resulting in service provision that does not adequately reflect their needs.

The PATHFINDER study was developed to address this gap by documenting and amplifying the experiences of carers from Somali and Gypsy and Traveller communities.

Aims of the study

The PATHFINDER study aimed to:

1. Explore informal caring practices among isolated ethnic minority carers, focusing on Somali and Gypsy and Traveller communities.
2. Investigate barriers to accessing health and social care support.
3. Identify how services could be adapted to become more culturally appropriate and accessible.

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[1] Carers UK (2024) Key facts and figures about caring. London: Carers UK. https://www.carersuk.org/policy-and-research/key-facts-and-figures

[2] Carers UK (2024) There are currently 5.7 million unpaid carers in the UK. Carers UK Press Release.

[3] The need for a new National Carers Strategy

[4] Hidden Carers UnHeard VoiCes informal caring within the Gypsy/Traveller community in Scotland

[5] Rapid review: Ten ways to improve support for minoritised informal adult carers at local government policy level to redress inequality

4. Facilitate multi-agency workshops with stakeholders to explore factors contributing to low engagement with services.
5. Develop resources and guidance to support culturally informed approaches to supporting ethnic minority carers.

What We Did

Narrative storytelling interviews were conducted using open and unstructured questions, allowing participants to share their caregiving experiences in ways that were most meaningful to them. This approach prioritised participants' own narratives about their caring roles and experiences accessing support.

A total of 12 interviews were conducted with women carers:

- **Gypsy and Traveller carers (n=5)** supporting parents, spouses, or relatives with long-term conditions

- **Somali carers (n=7)** supporting parents, disabled children, extended family members, or community members

Interviews with Gypsy and Traveller participants were conducted in person, reflecting community preferences for face-to-face engagement. Interviews with Somali carers were conducted both online and in person, with language support available where required.

In addition, two multi-agency co-production workshops were facilitated with: health and social care commissioners and providers, social prescribers, as well as voluntary and community sector organisations. These workshops enabled stakeholders to reflect on the findings and identify ways to improve engagement and culturally appropriate support.

Shared Experiences Across Communities

Several common themes emerged across both Somali and Gypsy and Traveller carers:

1. **Care as a cultural expectation** – caring for family members, particularly elders, was widely understood as part of the "circle of life."
2. **Gendered caregiving roles** – women were typically expected to undertake primary caregiving responsibilities.
3. **Stigma and shame** – seeking support outside the family may be viewed negatively, as caring for relatives is often seen as a family responsibility and asking for help can be perceived as neglect.
4. **Isolation** -many carers experienced social isolation and emotional strain due to limited support networks.

Findings from Somali Carers

Somali carers described caregiving as shaping their identity and everyday lives, particularly for those supporting elderly relatives. Some participants described finding meaning and purpose in the caregiving role.

However, mothers caring for children with disabilities often reported significant isolation due to stigma surrounding disability within the community. In some cases, families experienced social exclusion, leaving women to manage caregiving responsibilities with little support.

Religion played a significant role in supporting carers. Many participants described how Islamic teachings on compassion and care for those in need provided emotional strength and motivation.

Religious practices also influenced care arrangements. For example, some women explained that religious norms prevented them from providing personal care to men who were not their husbands, highlighting the importance of gender-sensitive service provision.

While most participants were open to engaging with formal support services, some lacked information about what services were available or what support they were eligible for.

Findings from Gypsy and Traveller Caregivers

Gypsy and Traveller caregivers emphasised strong family loyalty and responsibility in providing care for sick or ageing relatives. Caring was widely seen as a family duty rather than something to be shared with external services. A recurring theme was deep mistrust of healthcare and social care institutions rooted in both historical and contemporary experiences of discrimination and misunderstanding. Participants expressed concerns about privacy, fear of authorities, and worries that information shared with services could negatively affect their families.

Despite this mistrust, some participants described gradual shifts in attitudes and a willingness to engage with services when trust had been established.

Key factors supporting engagement included:

1. Respect for privacy and community boundaries
2. Open-mindedness and cultural awareness from professionals
3. Relationship-building over time. Participants emphasised that trust cannot be built quickly, particularly in communities with long histories of marginalisation.

Recommendations

The **PATHFINDER** study highlights the importance of culturally informed and trust-based approaches when supporting carers from marginalised communities.
Improving engagement with services requires:

1. Cultural competence training for health and social care professionals to improve understanding of ethnic minority communities and reduce stigma and discrimination.
2. Community-informed service design, involving carers and community organisations in the development of support services.
3. Improved information and outreach, ensuring carers are aware of available support and eligibility for services.
4. Gender-sensitive care provision, particularly where religious or cultural norms influence caregiving practices.
5. Long-term relationship-building with communities, recognising that trust develops gradually and requires consistent engagement.
6. Partnership working with voluntary and community organisations, which often act as trusted intermediaries between services and communities.

By centring the voices and experiences of Somali and Gypsy and Traveller carers, the **PATHFINDER** study provides valuable insights to support the development of more equitable, culturally responsive, and accessible social care services.

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Composite Narratives Exploring Carers' Lived Experiences

The collection of composite narratives developed from qualitative interviews conducted as part of the PATHFINDER study. Composite narratives combine insights from multiple participants into anonymised stories that reflect shared experiences, while protecting participant confidentiality.

These narratives illustrate key themes identified in the study, including caregiving expectations, experiences of stigma and isolation, engagement with health and social care services, and the role of culture and community in shaping caregiving practices.

Experiences of being a family caregiver

The first three composites discuss the themes around experiences of being a caregiver these include how the caregiving role is understood, who primarily takes it on and how caregiving is shared across the family. These composites further highlight the convergences in experiences across both cohorts.

ST1: The circle of life: from being cared for to becoming a carer

How caregivers conceptualise their caring responsibilities is crucial, because this then suggests how support is sought. When caregiving responsibilities are understood as a duty, accessing support especially for GT communities is seen as a sense of failure. Caregivers in both cohorts perceived the caregiver responsibility as the natural order of life, where they begin their lives receiving care as children from their parents, to then take on the same role for their parents in their time of need. As a result, self-identification as a carer was limited, which further meant they would not perceive services available to carers as relevant to them. This is explored in the composite titled ‘duty’.

Composite 1: Duty

> *“Financially it’s hit me quite hard, so then I’ve had to apply for carers[allowance] to help me financially, which I didn’t really want to do, but like my mum said to me, she said, but that’s what you are [a carer]. It just feels a bit weird being paid to do something you should already do, I just didn’t see the point in it really, why would you take money to care for your own mum? [1] At the time, it was my job, because I was her daughter.[3]” When I was a baby, when I wanted changing, or when I wanted washing, she’d done it. So yes, I did feel as though I should have been doing it. They’ve looked after you, you’ve got to return the favour, you’ve got to look after them.[4] It’s just natural, you see. He [Father] cared about us when we were so young, so we have to care for him when he’s old, you have to deal with it.... Because if I did today to him, tomorrow my kids, they’re going to do it to me [5]”.*

ST2: It’s the woman’s role to provide care

Fixed gender roles govern how the family caregiver role is primarily taken up, across both communities this role is a cultural expectation that will be fulfilled by a woman in the household, be it the wife, daughter in law, or daughter, caregiving is considered to fall within the roles and responsibilities of a woman. Reflecting on this, women often recall how they have grown up with this expectation, which almost served as a readiness to take on this role when it was eventually time to take on. This was particularly apparent when the caregiving responsibility was for a child with disabilities, the responsibility fell primarily to the mother, embodying the fixed gender norms further. This is explored in the composite titled “To be a woman means to care”.

Composite 2: To be a woman means to care

"I always knew it was going to come, because in our community it's a very natural role to go into [2], but it came way earlier than what I ever thought it was going to. I thought I may get to 40, 50 years old and then I would have to start doing things for my mum, it came a lot earlier than what it was. In the Gypsy community, no matter what we're doing personally, we are still mum and wife, housekeeper, cook, cleaner, whatever you want to call us, all those jobs still need to be done as well.

So, it's a bit of hard to keep it all going. And it's the stress to drive over to her and make sure that she's [mum] living in the condition she should be, and if she's eating, and especially when I'm already home and I have the care of the kids, I have to take them with me as well. I've got no choice; I've got to deal with it because there's nobody else to do it. So yeah, I'll have a little breakdown and maybe get a bottle of wine or however I deal with it, you just reset and keep going. And if their mobility ever went, we've already had that conversation, if it ever got to that point they would be living with me, my sisters have said again, that wouldn't be the boys role, it would be only the daughter's role.[1].

We wouldn't expect the boys to go and help wash or dress or anything like that, they wouldn't do that. I've had family members who have had to give injections daily for whatever reason and because the parent was refusing to have any outside help the daughter had to go and train and be told how to inject this medicine.[2]

We see it's getting more harder, but still we're pushing ourselves to accept it. And we'll see how long we can do that and see how long we can keep it. It is difficult to care for somebody, even though the task is that you're helping and you're making somebody else's life easier, but it's not something that I feel is a burden. The task itself is difficult, but I don't find it burdensome. [Caring as a mother however] I feel like motherhood is looked at as a penalty for life.

> *The African Somali culture it is very cruel towards mums and look at them as, this is your job, you're not supposed to have fun, you're not supposed to do, like, pursue anything else. If you take a break, like if you're seen outside doing something else, it's like, oh, the first question would be like, but who is looking after your child? Who is babysitting? The dad and he's not babysitting, it's his child too. I don't know, mum's carry a lot of burden, and they don't talk about it. I know that, like, the European culture is not like that."*

Understanding how caregiving is perceived within these communities suggests there is a need for additional psychosocial support where women can navigate their caregiving role healthily. The only difference to emerge between the two groups were within in Somali caregivers, men would support specific caregiving responsibilities (i.e., hygiene related) if the care recipient was of the opposite sex and not a child.

ST3: Caregiving is also a familial duty

There were some instances where other members of the family would support the primary family caregiver in the caregiving responsibilities. From the interviews, this was the closest the women came to receiving support showcasing some relief highlighted across the accounts. This is presented in the composite titled "*Family is the first port of call for extra help*".

Composite 3: Family is the first port of call for extra help

"I already know from my dad, from his hospitals, he wouldn't even let the nurse wash him, he wouldn't let the nurse do anything. My mum had to go in and do all that and then he was in there for a long time and when she wasn't able because of her mental health, she forgot or for whatever reason she forgot to visit him, it was left for me and her to go up in the evening time and give him his food because he wouldn't eat the hospital food. My husband he's saying that we can do it.
So, we didn't get any support, and we didn't look for other support. Sometimes, our kids, they support me and they take him to stay with them (father-in-law) so I get support from the family. If we choose in the future, it's going to be maybe cared for inside my house to come and just maybe for hygiene, or sometimes when we go out to look after him.
Looking after him, helping him home, those things we can do that, but we didn't need to do that hygiene stuff for the man because we get the support from the (male members of) family. [5]"

Caregiving within the wider community eco-system

The composite in this theme captures caregiving within the context of the participants respective collective community cultures. Two composites make up this theme and are presented below.

ST4: Navigating caregiving to prevent shame and stigma

Although both cultures were very different, the caregivers experienced echoed similar challenges but for different reasons, these composite captures this. For Somalian women, being a caregiver of child with disabilities meant they also had to navigate the cultural stigma and negative perceptions held around disabilities.

For women in the GT community, they were navigated similar challenges, but these were more related to navigating the cultural need for confidentiality. Maintaining the reputation of the family within the GT community is an utmost priority, which is placed above everything else.

As a result, GT communities become insular, the extreme importance given to privacy and maintain this within the wider community inadvertently prevents women receiving social support.

In both groups navigating cultural barriers resulted in experiences of isolation, increasing the likelihood of requiring psychological support. Participants had limited access to social support, and so also did not gain the benefits of social support that are often so crucial for family caregivers. This is captured in the composite titled "A culture of silence".

Composite 4: A culture of silence

“When it comes to neurodivergence and autism and those kind of disabilities with children, families, they keep it under wraps as much as possible. So, if it’s something like visible, like cerebral palsy or a child in a wheelchair, of course, then you have to say it. But if a child has autism unless he or she looks visibly severely autistic, they’re not going to mention it. But just treat them as a human being instead of someone with a disability. They seem to separate the two, especially in my culture. It’s just like they have a disability; we don’t need to pay much attention to them.[6] Disability is looked at as a taboo. Back home, if someone has a disability, they’ll be locked away. They will not be outside. Even here there’s a lot of families whose kids have disabilities. They keep them at home. They don’t get them out because people will talk, people will say, if you have disability in your household, people don’t want to marry into that household because they feel like it’s contagious. So, I made sure that I was isolating myself from the community. Because at the time, the community were not accepting of children with disabilities, it is stigmatised still. Once I isolated myself from the community, I put all my effort and my time into my children…

It goes back to the privacy, because you’re just telling everybody your business. They’re not going to help you, you’re not going to ask for help, so why would you tell them about your business in the first place? He [Dad] would probably be very upset with me, and I’d feel like I broke his trust because not even just our family, any Gypsy or Traveller family, it’s very confidential. You don’t talk about family business to anybody. [1] If their mobility went, how would that look if they would let me [get outside help]. It’s completely out of the question because again, it’s that shame in the community. What would I look like if I put my mum and dad in a care home?”

ST5: Finding comfort and support among the few

Some of the women did discuss finding their safe spaces where they could connect with others similar to them, highlighting what benefits this brought. Somalian women discussed that through the help that they received from their safe space and their faith; they choose to pave this forward to others in a similar situation to them. However, the potential for greater burnout is something that is not considered and should be a focus of services. This is captured in the composite titled "There are safe spaces within the community".

Composite 3: Family is the first port of call for extra help

> *"The thing that gives me comfort is my religion and talking with my close friends or family who understand what we go through, but the culture not so much.[2].*
> *But there were [women in the] community that stepped forward to help me.[1] It's important to have that circle of friends that are from the same background who would understand also the current situation.[2]*
> *We [women] do [talk] to an extent. We'll have a good moan about it or something like that. We won't go into detail.*
> *When I have time, instead of doing any other hobby or doing something else, I make sure that I go out of my way to help them and support them to make their life easier.[4]*
> *I see their struggles and they struggle painfully.*
> *So instead of just not doing anything about it, I have time to help. I can make a difference in their life and it's something innate in me to be able to do that, to help out.*
> *Emotionally just me looking at this person who is in need, and cannot change their circumstances, that itself is basically what is making me feel very emotionally difficult that's why I find it difficult[4]."*

The next composites that are discussed, present the divergences in experiences where perceptions of support, barriers to access support and what services need to be aware of when seeking to support informal caregivers from the GT and Somalian community.

GT1: Past harms, present judgement, how do we move forward from this cyclical pattern?

GT women reflected on past experiences of themselves as children and then more recently experiences with hospitals which illustrated that GT communities continue to feel misunderstood. Continuing to experience judgmental attitudes validates their reluctance to engage with services and alienate outside support. Many of the women perceived that social services and healthcare professionals misunderstood their way of life and had preconceptions and biases towards the GT community as a whole.

Some of the women spoke about how their childhood memories of GT children being taken away by social workers had made them wary of their intentions. Both of these past and present accounts collide to reinforce those services are not safe spaces for GT communities, feeling embarrassed and experiencing judgemental attitudes suggested a need for cultural awareness training but also training in basic communication standards that represent non-judgemental patient centred care. This composite is shared through the voice of Ciara.

Composite 6: Ciara – is the past really in the past?

"Our whole life as a child, we were roadside, and social workers only came for one thing. If kids weren't at the education, they'd take the kids. [3] We've learnt our whole life that social workers are just there for taking your kids, and that's it. No help, no support, no nothing.
So, we grew up with all that in our life. Now, I've had meetings in the past with social worker groups, and the opinion they had on the travelling community, English and Irish, I just couldn't believe it, they basically said that travelling people have no right to healthcare, no social care, and no education and that's not true. And that is the opinion that they have. So, before, like, if they're getting called out to a family from either an English or Irish community, from the travelling community, they go with that in their head anyway.
So, it's not a good start, is it?[2] They might think that you live in poor conditions because you're in trailers and whatnot, but until you're there and you can see these people need help, they're not bad people, they don't live in a bad way. They're clean and whatever. Like just be open-minded and willing to listen, see what's what, before you've made a judgement, before you even get there, and then assess the situation.[4]
"When you're in a hospital situation you may talk to multiple different professionals in there and every time you have to explain who you are, why you're there - yes this is wife, this is daughter, I'm here for this, it is a bit tiring, Some of them got it straight away and was fine with it, some questioned it and it's a bit embarrassing when the people find it strange and don't want to cooperate, you have to persist because you've got no choice, you can tell she [HCP] isn't going to take you in [to the consultation]. you but maybe just take the time to ask, why are you here, is there a reason why you have so many family members?
If there isn't, then yeah, you can ask them to kindly leave. They may just be there to show respect or to, you know, whatever it may be, but nine times out of ten, there will be a reason why you have multiple people in that room, which again, I know

> *it's not great for them, because they just want to deal with the patient, and that's it.*
> *If you want to know something just ask the question because we just need to know what's wrong with them. We need them sorting, so then we can carry on with getting them better or looking after them.[4]"*

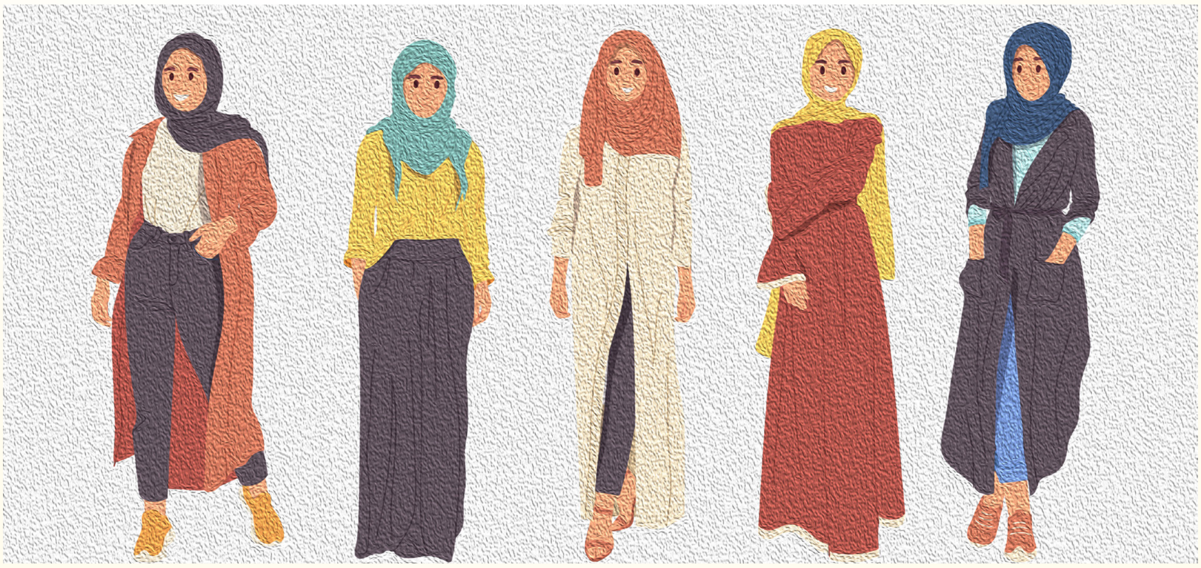
S1: We welcome support, but is the support culturally aware?

When Somali women were made aware of services relevant for them, they welcomed their support and would access them, however they vocalised culturally aware services would ease the fears and mistrust they hold. This is account is shared through Hibbah's story.

Composite 7: Hibbah: Know my community and understand our cultural needs

> *"My early support team was helping me to educate the two boys and after that, the visual support team, they gave me very huge help. And [Charity], as well, they gave me huge, huge support for the family and the boys [1] The Family Support Worker gives me a lot of support, emotionally, physically, everything, and if I have any problem, if I call her, she's always supported me, just like a mother's role, somebody, just like my mother would.[1] The NHS, they helped me about feeding, language therapy, the coming home, my home visits.[5]*
> *I get in touch with her teachers of the deaf to figure out if there's anything else we can do to support at home.[6]*
> *But I didn't know about speech and language therapies,*

didn't know about play teachers, teachers of the deaf. I didn't know anything about that [6] and many of them they don't know their rights. I spoke with a couple of mums telling them you do realise you have to apply for x, y and z, you can get help with this and that and they didn't know.[2]
[But] if you have outside carers then there's more to be aware of, for example female people in the disability, they need female carers, males need male carers. If you wanted to have a carer, it should be in your language, because it's more helpful.
You cannot enter somebody's household wearing shoes and they have to be aware of the religion aspect of it. For example, you cannot come in someone's house drinking or drunk or with pork or anything like that. [6] But within the Somali community they like to differentiate females take care of the females and the males take care of the males, which is difficult.
If it's a household full of girls and a single father, what's going to happen then?[3] That's when usually they rely on outside carers and they have to be male carers.[5]
I'm always fearful of those people that I come across, are they going to help me? Or are they going to cause me any pain? Will they be supportive? Or will it be causing some kind of problems for me and my children? So, it was always fear-based. It was always, how am I going to get good support [1]."



Change is coming but it’s going to take time

The final composite aims to highlight generational change, whilst historically these communities have largely been ignored and isolated, upcoming generations within the communities are attempting to champion for change and so the communities remained hopeful that these experiences will not always be their reality. Whilst attitudes are changing and support is being requested, there is still some way to go, this was particularly apt for the GT community who highlighted that rebuilding trust takes time and there is still some way to go before services are perceived as safe for them. The reflections of the differences between older and younger generations in both cohorts represent an ongoing battle for change, whilst providing social care services with some key ways to engage with the communities particularly through the younger generation.

Composite 8: We do want support, but we need you to be patient.

“It all depends on how open-minded the family is. I mean, I know some of the older generation, they are a bit more open-minded now. And some of them will accept the help, but there is still a lot out there who will not accept the help. It depends on how open-minded the family is [4].
As the generations are coming on, things are changing, but that was my generation. Some people on the sites, they’re all there, so they just run around and do what they’ve got to do. But they’re in the houses now, so a lot of them are turning around and saying, just have these people in now to make your sandwich, do this, do that, and some of them
are accepting it, but as far as I know, a lot out there are still not accepting it, because it’s a private community and they’re very private people, and they feel as though they’re being pried on. If they’re [social care workers] just being friendly and saying, oh, what are you doing tomorrow, and they turn around and say, well, what do you want to know that for?
In the older generation, it’s felt as though they’re prying.[3]

> *“They [older generations] won’t let anybody into their lives.[1] It’s getting through that door. And once you get in that door you can see. you’d have to go to the children, or the grandchildren, to see how to get in. Then we’d probably go in and explain why you’re there, why you’re trying to help, and I’d probably turn around and say then, well okay then, let’s give it a go.[3]*
> *I think the older generation, they will care and care until they run out of fuel. They will [do] the minimum self-care for themselves. Yes, they will eat and wash and clean themselves and sleep, but they will not take care of the brain, they will not take care of their physical health.*
> *Any idea about taking a break, sleeping, going on holiday, just have respite, they don’t believe in it. I see a young mum my age, okay, a mum who is younger than me actually who has got a child with a wheelchair I think, cerebral palsy, she leaves her kids with the very lovely supportive husband and goes away and sees her family in a different country and I’m happy, this is so refreshing. Every time I see her doing that, I am so happy for her because that was not the case thirty years ago.*
> *Thirty years ago, you’ve got a child, that’s it, you bury yourself alive with the responsibility[2].”*

Appendices

The following appendices provide practical guidance developed from the findings of the PATHFINDER study as part of the co-production workshops.

Appendix 1

Culturally Competent Care Services – Key Considerations for Engagement with Somali Carers

This document outlines key cultural, social, and practical considerations for health and social care professionals when engaging with carers from Somali communities. It highlights factors such as the role of religion, gender-sensitive care provision, stigma surrounding disability, and the importance of community organisations in supporting carers.

Appendix 2

Culturally Competent Care Services – Key Considerations for Engagement with Gypsy and Traveller Carers

This document presents key considerations for engaging with carers from Gypsy and Traveller communities. It highlights the importance of trust-building, respect for privacy and family autonomy, cultural awareness among professionals, and the role of community advocates in improving engagement with services.

Culturally Competent Care Services – Key Considerations for Engagement with Somalian Carers

DO: ✓

- Recognise the intensity of the caring role. Many carers feel invisible, as attention focuses solely on the person being cared for.

- Acknowledge the hidden risk of burnout. Women supporting both their own families and others are at increased risk of emotional and physical exhaustion

- Caring, especially for children with disabilities or elder relatives, is often seen as a lifelong moral duty, particularly for women.

- Be aware of isolation linked to disability. Somali mothers caring for children with disabilities may experience isolation due to cultural perceptions and lack of open discussion about disability.
  Do understand stigma around disability

- Offer support proactively and frame services as complementary. Outside help is often welcomed, particularly where community support is limited or unavailable. Emphasise that formal support can support family care, not replace it.

- Explain entitlements and services clearly. Many carers are unaware of their rights, benefits, and available support. Don't assume knowledge.

- Respect religious and cultural practices.

- Same-gender care may be essential. Women may not be permitted to provide personal care to men who are not their husbands

- Be mindful of modesty, language needs, household practices, and faith sensitivities

- Religion can be seen as a potential strength. Faith can provide resilience and validation for seeking support, even when cultural stigma exists.

Culturally Competent Care Services – Key Considerations for Engagement with Somalian Carers

DON’T: ✖

- Don’t assume carers will speak up about their own needs
- Emotional and psychological distress is often hidden due to expectations of strength and resilience.
- Don’t focus only on the cared-for person. Ignoring the carer reinforces feelings of invisibility and burnout.
- Don’t underestimate the impact of stigma. Isolation linked to disability is real and can shape how carers engage with services.
- Don’t make assumptions about family or community support. Support within the community may be limited, strained, or completely absent.
- Don’t overlook gender and religious boundaries. Assigning inappropriate carers or ignoring faith-based rules can seriously damage trust.
- For many caregivers, faith supports help-seeking
- Don’t use jargon or vague explanations. Lack of clear information can be a major barrier to accessing support.
- Don’t expect carers to prioritise themselves without reassurance
- Self-care may feel selfish or irresponsible without explicit validation.

Culturally Competent Care Services – Key Considerations for Engagement with Gypsy and Traveller Carers

DO: ✓

- Recognise that many women do not see themselves as carers. Caring for older family members is viewed as a normal part of life and family responsibility (“the circle of life”), rather than a distinct role or burden.
- Respect family hierarchy and decision-making structures. Elders often hold authority. Engagement is more successful when approached via trusted younger family members first.
- Trust is personal and earned. Be genuine, patient, and transparent about your role and intentions. build trust slowly and consistently
- Acknowledge historical trauma and mistrust of services. Past experiences with social care (especially child removal) shape current fears.
- Respect strong expectations of privacy. Among Gypsy and Traveller communities, asking for help may be seen as exposing private family matters and bringing shame on the wider family.
- Explain clearly why information is being asked for.
- Ask rather than assume. Simple, honest questions are often better received than “professional curiosity.”
- Involve family members appropriately. Multiple relatives present is often a sign of respect and support, not interference.
- Be culturally aware and non-judgemental. Engage with community organisations and partners to seek advice and guidance on cultural nuances and culturally appropriate practices.
- Understand traditions around gender roles, caring expectations, and community life without stereotyping.
- Focus on practical, acceptable support
- Challenge internal biases and assumptions
- Be open-minded about living conditions, family dynamics, and what “good care” looks like.

Culturally Competent Care Services – Key Considerations for Engagement with Gypsy and Traveller Carers

DON’T: ❌

- Don’t assume carers want or will accept formal support services. Especially personal care or care homes, which may be viewed as shameful or a last resort.
- Don’t go straight to older family members without guidance. This can be seen as intrusive. Bypassing family channels risks immediate disengagement.
- Don’t ask about personal or family matters unnecessarily. Casual questioning can be interpreted as surveillance or judgement.
- Don’t dismiss fears of social care involvement and previous, including previous experiences that may have been negative.
- Don’t use jargon and complicated language
- Avoid framing communities as “hard to reach” or “non-compliant.”
- Don’t treat the community as homogenous
- Don’t apply rigid, ‘by-the-book’ approaches. Flexibility and relational engagement are often more effective than strict procedural adherence.
- Don’t question family presence without explanation. If limits are needed (e.g. in hospital settings), explain respectfully and ask, don’t order.
- Don’t assume lack of engagement equals lack of need
- Many carers experience significant strain but cope silently due to cultural expectations.

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