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EVIDENCE BRIEFING

Key factors that affect access to support for minoritised informal adult carers that can be addressed at local policy level

FINAL DRAFT

30 November 2023

Bradford Council Health Determinants Research Collaboration (HDRC) / University of York Policy Research Hub

SUMMARY

Aim

- To rapidly identify and summarise evidence on key factors that affect access to support for minoritised informal (unpaid) adult carers, which can be addressed at local policy level

Methods

- Rapid umbrella review of systematic reviews
- Systematic reviews were identified through 'pearl growing' initial literature identified by an expert group (n=4), complemented by simple database searches (Medline, Cochrane, Proquest) in September-October 2023
- Systematic review evidence was supplemented with practice-reports
- Data was extracted directly into a table and findings synthesised narratively by theme

Key findings

- Many factors were identified in existing literature as affecting access to support for minoritised informal adult carers, including: inattention to socio-cultural diversity; issues of representation, racism and discrimination; and socio-economic inequality.
- Factors identified were themed around ten areas for local action:

1. **Recognise diversity within minoritised groups**
2. **Ensure support is socio-culturally appropriate**
3. **Recognise different understandings of care and carer coping strategies within local policy development and support service design**
4. **Ensure gendered hierarchies and inequalities in care work are considered when developing support**
5. **Identify racism and discrimination and 'design it out' of services**
6. **Ensure access to social networks for support, influence and voice**
7. **Address exclusions that adult carers with additional communication needs face**
8. **Identify and mitigate socio-economic inequalities**
9. **Ensure representation of minoritised adult carers in systems of support**
10. **Ensure there is a 'whole system approach' to support carers, including attention to improving data systems and evaluation**

1. INTRODUCTION

This evidence briefing provides insight into key factors that affect access to support for minoritised informal adult carers, which can be addressed at local policy level. It also identifies examples of opportunities for local action.

Informal caregivers have an essential and growing role in Bradford and the UK, looking after an increasing number of people in need of long-term care (1,2). An informal carer can be understood as someone who helps look after a family member, neighbour or friend without being paid; for example, providing personal care, monitoring medications, and/or practical tasks, including shopping and helping with finances (3,4).

Informal carers have an important role within the Bradford health and care system (5) but taking on a caring role, particularly if it involves long hours of care, is known to have significant impacts on people's lives, health and wellbeing: often resulting in poorer physical and mental health, and quality of life (1,5,6). It is therefore essential that informal carers receive the support they need.

Supporting carers can take different forms, including wellbeing or advocacy services directly targeted to them, workplace support, and peer support via social networks within communities; and involving practical (including financial), physical or psycho-social assistance (1,5). While the importance of quality support is established and there is policy interest in achieving this in Bradford and across the UK, little is known about factors that shape access to support at a local level, particularly for minoritised carers (7,8,9,10), defined here as:

> *"individuals and populations (including numerical majorities) whose collective cultural, economic, political and social power [access to resources and health] has been eroded through the targeting of identity [including based on ethnicity, language, religion, age, sexuality, migration status, disability, neurodiversity, socio-economic background)] in active social processes that sustain [existing systems of dominance]"* (11)

A rapid review was therefore completed on this topic to inform local action.

2. METHODS

A rapid umbrella review of systematic reviews was completed. Standard methods do not exist for rapid reviews, particularly for those not primarily focused on intervention effectiveness. Relevant Cochrane (12) and Health Policy and Systems guidance (13) was therefore modified for applicability here.

Systematic reviews were identified through 'pearl growing' initial papers identified by topic experts (n=2), and was complemented by simple database searches in September-October 2023. Systematic review evidence was supplemented with practice-reports identified by experts as locally-relevant.

Data was extracted directly into a table and findings synthesised narratively by theme. Only a small proportion of reported data was relevant in some SRs, with a lack of detailed evidence overall on the topic. Consequently, and in line with other recent rapidi reviews (14), it was decided that formal quality assessment of each source would not be particularly informative or appropriate

34 evidence sources were identified and used

27 systematic reviews
7 practice reports

A note about language

This briefing adopts the approach of the NHS Race and Health Observatory with regards to language, recognising that “language has power” and that the terminology we use when talking about different people and groups can have real world impact.

The briefing is guided by the Observatory’s principles when talking about minoritised groups, particularly those who are minoritised on the basis of race and ethnicity:

- the briefing tries to be as specific as possible when discussing different people and minoritised groups, only using collective terminology where there is a legitimate need to do so
- where collective terminology is needed and the context is unclear, collective terms such as ‘minoritised ethnic groups’ ‘ethnically minoritised groups’ ‘Black, Asian and other minoritised ethnic groups’ are used
- because the briefing synthesises wider research which does not use terms that reflect this preferred approach, there may be occasions where other terminology is used
- the acronyms or initialisms BME or BAME will not be used
- the collective term LGBTQ+ is used
- it is recognised that no one term is suitable to respect the diversity of people’s experiences and our use of the above terms is underpinned by respect for individual and community dignity

Comments on the briefing and the language used are welcomed, with a view to changing the approach used in the future.

3. KEY FINDINGS

Many factors were identified as affecting access to support for minoritised adult carers, including: inattention to socio-cultural diversity; issues of representation, racism and discrimination; and socio-economic inequality. Factors were themed around ten areas for local action:

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1 **Recognise diversity withn minoritised groups**: Minoritised adult carers have diverse identities, needs and experiences. There are risks of exclusion when there is inattention to such diversity and to experiences racism and discrimination within systems of support (11,15,16,17).

To address intersecting inequalities, local policy needs to:

- recognise and value diversity
- commit to changing the status quo of service planning and delivery; and
- proactively identify and engage with unpaid adult carers in minoritised groups to redress barriers, marginalisation and unequal influence within health and care systems (15,16,18,19).

2 **Ensure support is socio-culturally acceptable:** There are limitations in health and care systems around the delivery of socio-culturally-acceptable support (e.g. heteronormative assumptions. ethnocentrism) which excludes caregivers in minoritised groups, leading to withdrawal from, or lack of use of, support services (9,17,20,21).

Minoritised carers (including of Black and Asian backgrounds, Chinese diaspora carers, Gypsy, Roma and Traveller carers, refugee, asylum seeker and migrant arers, LGBTQ+ carers, carers with a disability, and carers with autism) are more likely to feel services do not meet their needs, have concerns and/or experience difficulties in accessing support (9,15,16,22).

It is unclear what socio-culturally-acceptable support means in practice. While some carers may prefer culturally 'matched' providers, receiving support from skilled, respectful, and culturally-sensitive providers may be acceptable (18).

Local action could usefully involve:

- Investigating how existing support may disadvantage in hidden ways (22,23,24)
- Ensuring staff have socio-cultural knowledge and competencies (16,20)
- Coproducing support services with carers in minoritised groups - to recitfy deficits in influence, enable learning about different needs and ensure these can be met (15,16,17)
- Delivering support within a 'cultural humility' learning framework, focusing on not making assumptions about people's background, identity, or needs; critical self-reflection; and recognition of power imbalances (15,16,18)

3 **Recognise different understandings of care and carer coping strategies within local policy development and support service design:** Different cultural understandings of care (e.g. given that ‘carer’ does not translate in some languages including Bengali, Gujarati, Urdu, Punjabi) and expectations about “familial duty” mean that some carers, including in minoritised ethnicities, may primarily see themselves as a family member or friend, shaping whether, how and when support is accessed (3,8,16,21,22,23,25).

If parental caring is an expected duty, caregivers may feel unappreciated by family and friends, and embarrassment or shame about accessing support, taking a break, or seeking employment (16). Socio-cultural norms, and experiences of discrimination, can also shape coping strategies (26). Norms can also affect understandings of a stigma around certain health conditions (e.g. dementia, mental health) (23,27).

Local action could usefully involve:

- Targeted outreach to reach minoritised carers (e.g. working with community figures, leveraging relationships of voluntary/faith organisations, including language providers to reach refugees and people seeking sanctuary), to enable recognition as a ‘carer’ and access to support (8,15,16)
- Outreach may help reach carers who would not consider a ‘Carers Assessment’: ‘assessment’ can be perceived as a caregiving judgement and particularly stigmatising for LGBTQ+ and/or disabled carers

4 **Ensure gendered hierarchies and inequalities in care work are considered when developing support**: Gendered expectations and hierarchies mean women are often expected to become caregivers, across cultures and ethnicities, but can particularly be the case for women in some racially and ethnically minoritised groups, including in the context of intergenerational caregiving within South Asian communities (11,21,23,25)

Local policy action could usefully include:

- Consideration of gendered responsibilities, hierarchies and inequalities in care work, building this into the development of support (25)

5 **Identify racism and discrimination and ‘design it out’ of services**: Racism and discrimination exacerbate the challenge of caregiving for minoritised groups (8). Inequality in access to, experiences of, and outcomes of services are rooted in experiences of racism, discrimination and marginalisation (8,19,22).

Research highlights racism, discrimination and disrespect (including use of cultural stereotypes, preconceptions), ethnocentrism and service gatekeeping in relation to care and support, shaping carer wellbeing, access and preferences, and leading to distrust, frustration, cessation of support service use (29,30,31,32).

Local action could include:

- Creating safe spaces for staff and carers to have open conversations about race, ethnicity, sexuality, and other aspects of identity - to build trust and address past negative experiences (15,16)
- Staff training in anti-racist and/or anti-discrimination pedagogy (18)
- Ensuring adult carers disclosing racism and/or discrimination are referred to advocacy and rights-based support (27)

6 **Ensure access to social networks for support, influence and voice:** Strong social networks provide adult carers with emotional and practical assistance (5). Isolated carers can struggle to find help and are at greater risk of poor mental and physical health. Strong social ties within some ethnically minoritised groups , including South Asian communities, can be undermined by caregiving (21).

It is important that all carers can access support from their wider socio-cultural communities (20,21), but such networks can be particularly important for carers in minoritised groups, given societal marginalisation and discrimination. For example, difficult or estranged family relationships, when families are not accepting of LGBTQ+ identity, can isolate LGBTQ+ carers, with implications for belonging and self-esteem (15).

Opportunities for local action include:

- Ensuring carers can access peer support to share experiences, exert voice, receive emotional support and practical advice (5)
- Socio-culturally matched support may be preferred by carers from minoritised ethnicities and some LGBTQ+ carers might appreciate LGBTQ+ specific groups - other carers might prefer to focus on their caring role, so speak to carers about what they need, rather than making assumptions (15,16,32)
- Holding support groups in trusted spaces (e.g. religious/community centres) (16)
- Co-hosting events with local cultural forums may promote involvement (16)

7 **Address exclusions that adult carers with additional communication needs face:** Adult carers with additional communication needs (e.g. physical, sensory or learning disabilities, people who do not speak or read English fluently – including some recent migrants) may experience exclusions from support if designed around dominant ways of communicating (16,21,28,34).

Written and spoken levels of English fluency vary across different groups, including, for example, older people with histories of migration to Europe, with lower levels reported amongst some Pakistani, Bangladeshi, Chinese, Vietnamese, Somali older people in the UK (28).

Opportunities for local action include:

- Offer extra communication support (e.g. interpreters, sign language) to bridge gaps in communication and improve support (16)
- Provide translated, multilingual resources in people's preferred languages - consulting relevant local groups and carers themselves about whether materials would be useful, in which languages, who might benefit and how materials could be shared (16)
- Leverage expertise of voluntary and community groups who work with different minoritised groups (9,16)
- Consider if using outreach services, Carers Champions, Ambassadors and/or carer Buddies to disseminate information, enable access and be a route to peer support would be useful – particularly for carers with social anxiety or lacking confidence in social situations (8,15,16)

- Consider if personal support workers could help minoritised caregivers feel more comfortable expressing their needs - but evaluate and engage carers to ensure this type of support does not lead to unwanted feelings of dependency (21,28)
- Recruit staff and/or volunteers with the socio-cultural competences (e.g. additional language skills, understanding of particular cultures/ethnicities, lived experience of caring) to help provide targeted support (e.g. ensuring these are expressed as desirable or essential job description criteria for roles involving engaging with carers (16)
- Consider if digital support technologies could be useful (e.g. to translate information, support carers) for those not fluent in English or with other communication needs, but be aware of potential ethnic and/or socio-economic inequalities in digital access - evidence here is limited (16,19,35)

8 **Identify and mitigate socio-economic inequalities and support livelihoods:** Minoritised adult carers often face intersecting socio-economic inequalities that affect access to support: financial resources are a critical factor affecting the support unpaid carers receive (9).

Many carers across all social groups find they have higher bills, need to reduce working hours or quit jobs, with income loss causing significant financial strain (5).

The cost-of-living crisis is putting pressure on carers, with a quarter cutting back on essentials (9). Practice-reports also highlight that carers from Black, Asian and minority ethnic backgrounds are more anxious about their financial situation and more impacted by local service closures than White carers (9,16).

The need for financial, housing, mental health and/or access to employment support is highlighted in studies with ethnic minority carers to mitigate adverse material circumstances linked to societal marginalisation and discrimination (27).

Local action could include:

- Support carers livelihoods by helping carers stay in or return to work, or access social security is crucial, particularly for minoritised women who often do most care work (9)
- Targeted carer financial, benefits advice can help alleviate financial caregiving burdens - and can be particularly important for caregivers to people recovering from mental health conditions (27)
- Promote workplace support policies that include: flexibility to enable carers to juggle work and care; access to paid carer's leave; and explicit recognition of carer skills in recruitment and promotion (36,37)

9 **Ensure representation of minoritised unpaid adult carers in systems of support:** Lack of diverse representation of minoritised groups in support organisations, healthcare and policymaking can affect the sufficiency and appropriateness of support (9,20). Minoritised carers may feel they have 'no voice' locally and unable to raise service concerns (16).

Local action:

- Ensure diverse representation in decision-making can lead to more inclusive and culturally-sensitive support initiatives (9,16)

10 **Ensure there is a 'whole system approach' to support carers, including attention to improving data systems and evaluation:** Minoritised adult carers are more likely to have poor physical and mental health and carers who are unable to address their wellbeing needs find it increasingly challenging to caregive effectively (5,8). This has knock on effects for those they care for, local service demand and prescribing costs (5).

A whole system approach, involving collaboration and integration across health and social care is essential to support carer wellbeing and coherently redress deficits in influence, racism, discrimination, and marginalisation (9,16). Multidisciplinary input from across government and voluntary sector health and social care is important.

Key areas for integrated action include:

- Carers Assessments - Black, Asian and other minoritised ethnic groups, and lesbian, gay and bisexual carers, are less likely to have had an assessment compared to White carers and heterosexual carers respectively (5)
- Improving data systems - including disaggregated demographic and diversity data on service participation, improved data sharing between carer support organisations, and ensuring data collection approaches and questions are socio-culturally appropriate (8,10,15,16,33,35)

- Improving evaluation - more process and mixed method impact evaluations of support services are needed, using theories of change and exploring what worked well or less well, why and for whom, focusing on different outcomes of interest to different unpaid adult carers and taking into account culture, ethnicity, and structural inequality (8,16,38)

Other example elements of an integrated local approach include:

- Develop a **strategic approach** to identifying and supporting carers **across all health and social care** partners and delivery mechanisms – ensuring this is co-produced with minoritised groups (5,15,16)
- Ensure **wellbeing support for carers** is part of the **public health prevention agenda (**e.g. include unpaid carers in public health, social prescribing and physical activity/leisure strategies) (9)
- Develop a strategic approach to **continuity in care** (e.g. same service provider in the community, availability of services) to ensure **sustained rapport and trust-building - relational continuity** can be particularly important when workers are not of the same ethnicity, particularly for South Asian individuals with non-English speaking fluency (16,21)
- **Prioritise hospital, GP appointments** for carers, and offer **longer** appointments and **flexibility** (e.g. home visits) to ensure carers can access help at a time and place that suits them (9)
- Ensure all **health professionals are aware of carers assessment** (e.g. via training) and actively signpost to local support organisations (9)
- Ensure that **carers assessments are linked** to hospital discharges, part of intermediate care provision and continuing healthcare packages of support (9)
- Ensure carer **wellbeing services are flexible and adaptive** to the socio-cultural needs of different carers (e.g. **socio-culturally- adapted psychosocial suppor**t) (39,40)

4. SUMMARY OF LOCAL OPPORTNITIES FOR ACTION

Whole system approach	• **Collaborate** across all health and social care partners and delivery mechanisms, so carers are identified and supported systematically and treated as partners in care • Ensure all system partners **commit** to **identify** and **redress barriers, discrimination** and **marginalisation** that minoritised groups face in accessing support • Ensure **diverse representation in decision-making** bodies • Embed a focus on carers' needs, particularly minoritised groups, in the **wider public health prevention agenda**, with carers considered, for example, when devising public health strategies (e.g. social prescribing, physical activity policies) • Coordinate strategically across partners to improve **access to carers assessments** (ie. ensuring links to hospital discharges, and part of intermediate care provision and continuing healthcare packages of support) • Consider how any issues of **continuity in care**, including **relational continuity** can be addressed, as this can be particularly important when supporting unpaid carers from minoritised groups who may have experienced racism, discrimination and/or who have additional communitcation needs • **Review**, with involvement of unpaid carers and local partners, how to **improve data systems** and **evaluation** of support
Socio-culturally appropriate service design	• **Involve carers** from minoritised groups in service design (ie. **coproduction**), paying particular attention to issues of **gender -** leveraging their expertise to **identify strengths** and **opportunities** to improve the provision of socio-culturally appropriate services across the local system • **Involve local partners**, particularly local organisations that work with minoritised groups, in service design • **Ask** unpaid carers about how they **understand 'care'** and carers **'assessments',** as well as their **preferences** for receiving 'culturally and linguistically matched' support and/or support from skilled, respectful, and culturally sensitive providers • Consider and **discuss** the use and value of **targeted outreach**, **carers champions/ambassadors/buddies**, working with local **gatekeepers** to develop **community-based support** services, use of **interpreters** • **Discuss** how the NHS/GPs could ensure that all carers, including in minoritsed groups, can get the help they need at a time and place that suits them (e.g. appointment flexibility/ priority, home visits) • **Ask** unpaid carers in minoritised groups what kinds of **social support** they need and value (do not make assumptions) - this includes trusted spaces for **peer support groups** to meet

Socio-culturally competent service delivery	• **Recruit** staff and volunteers with the expertise to engage and support minoritised groups (ie. make sure job descriptions reflect skills needed, e.g. speaking multiple languages where relevant) • Ensure staff and volunteers (local authority, NHS, social care, voluntary sector) are **trained** in, and have opportunities to **continuously learn** about socio-cultural differences and the provision of empowering and respectful support (e.g. anti-racism/anti-discrimination training pedagogy, spaces for open and honest conversations) • Ensure health professionals are **aware of carers assessments** (ie. via training) and know how to signpost to socio-culturally appropriate support locally • Ensure unpaid **carers are offered training** (e.g. structured programmes, one-to-one guidance on how to provide care, mental health recovery training) in ways that are socially- and culturally- appropriate • **Mark different cultural and social events** - developing these with unpaid carers from minoritised groups to ensure inclusion - and recognise that these can be opportunities for **shared learning** • Ensure **data systems** track outcomes and support services are **evaluated** (e.g. theory of change, mixed methods, participatory research) - this includes seeking and capturing feedback from unpaid carers in minoritised groups to understand whether support is beneficial, and making changes based on this learning • **Leverage the expertise of voluntary and community groups** who work with different minoritised groups (e.g. refugees and asylum seekers) to find out how support is working
Carers' livelihoods and economic security	• Ensure support services can support unpaid carers with issues of **financial insecurity** and distress (ie. **targeted financial assistance,** social security/benefits **advice**) • Ensure adult carers expressing concerns relating to discrimination, legal, and economic circumstances can be referred to and access **appropriate advocacy support** • Engage with workplaces to **develop workplace strategies** that recognise the importance of supporting carers (e.g. paid Carer's Leave, carer skills recognition)
Addressing inequalities in carer's health and wellbeing	• NHS and GP practices **prioritise appointments** for carers, offer **longer appointments** for carers and **flexibility** with appointments, including the possibility of home visits, to ensure carers can get the help they need at a time and place that suits them • Provide unpaid carers with **psychosocial support**, tailored to different stages of and transitions in caring, and ensuring it is provided in socially and culturally appropriate locations and formats • Ensure that enabling carers to live healthy lives is part of the **public health prevention agenda**, with carers considered when devising **public health strategies**, including **social prescribing** and **physical activity policies** (e.g. to ensure unpaid carers can access physical and mental health support at times, in places and in ways that are sociall- and culturally- appropriate)

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