

EXPERIENCES OF UNPAID CARERS FROM BLACK AND MINORITY ETHNIC COMMUNITIES REPORT – SUMMARY

BACKGROUND

The Social Services and Well-being (Wales) Act 2014, defines a carer as someone who provides unpaid care to an adult or disabled child. The cared for person may be a family member or a friend, who due to illness, disability, a mental health problem or an addiction cannot cope without their support.

Research has explored experiences and support needs of Black and minority ethnic carers in the UK (Greenwood et al. 2014¹, Carers UK 2022²) but more needs to be known about the situation in Wales.

Carers Trust Wales wanted to listen and further understand experiences of unpaid carers from Black and minority ethnic communities in Wales to identify, raise awareness and highlight solutions to specific challenges and requirements.

The **aims and objectives** of the project were as follows:

- To understand the experiences of carers of all ages from Black and minority ethnic communities in Wales
- Recommend actions and activities for local authorities, Welsh Government, NHS Wales and the health and social care sector more widely to improve provision for carers from ethnic minorities
- Recommend actions and activities for Carers Trust Wales and other local organisations to support the provision for carers from ethnic minorities

METHODS

In order to achieve this, we conducted 23 semi-structured interviews with unpaid carers from Black and minority ethnic communities. These were either online, on the telephone or face to face. Interviews were then analysed with key themes identified.

FINDINGS

- The overarching theme is a 'lack of fit' between support and services available and the needs of unpaid carers from Black and minority ethnic communities.

¹Greenwood, N. Habibi, R. Smith, R. and Manthorpe, J. (2014). Barriers to access Black and minority ethnic carers' satisfaction with social care services in the community: a systematic review of qualitative and quantitative literature Health and Social Care in the Community: Special Issue 23:1 pp.64-78.

²Carers UK (2022). The experiences of Black, Asian and minority ethnic carers during and beyond the COVID-19 pandemic Carers UK, London.

- There are **practical barriers** to receiving support. These include:
 - A general lack of awareness of carer rights and services that might be available. Very few carers had ever had it explained to them what support might be available with some assuming their life circumstances meant they were ineligible anyway.
 - Language barriers for some carers and/or the person they care for which hinders access, understanding and opportunities to benefit from any support on offer.
 - A lack of reliable support at home. Care providers would often be late or not arrive at all, leading to more stress than if they had not been allocated in the first place.
 - Inappropriateness of service support. There were often challenges meeting the cultural needs of individuals concerned such as ensuring time was set aside for prayer or meals were made using halal food.
 - A lack of cultural sensitivity on the part of providers. It is not just the more practical elements of providing support that might prove to be a barrier. A lack of understanding of the service provider to the manner in which the family live their lives can lead to misalignment and a breakdown in communication.
 - Differing concepts of what constitutes 'care'. By having a different understanding as what it is to 'provide care' in the first place is also likely to produce difficulties in reaching common ground when it comes to organising care provision. In western culture, care can be organised around 'time' and 'tasks'. This often does not resonate with communities who have a more holistic sense of care.
- There are **cultural expectations** within the local community regarding the carer role. This has an impact on the capacity to seek support. Barriers include:
 - Care considered part of 'family responsibility'. Many tasks associated with care are felt to be part of the role of the family and therefore not regarded by the community as 'additional' or requiring external support.
 - Community pressure to both undertake care work without complaint, particularly in public. This can make the opportunity and motivation to reach out for additional support challenging.
 - Gendered roles and responsibilities. Whilst an increasing number of males in the family contribute to care tasks, the expectation predominantly lies with females and, as a result, communal reaction to women undertaking care work differs to men. For example, when a mother took a break from her caring role, even for a short period, others felt she was neglecting her responsibilities. This was not the case for her husband.
 - **Perceptions of what it is to be a carer** means that many carers do not access support. Lack of self-identification as a carer is an issue amongst the wider population but this is particularly prevalent amongst unpaid carers from minority ethnic communities.
 - This has an impact on the health and well-being of the carer. Many would struggle with both their physical and psychological health rather than access suitable support.
 - There are also different perceptions and understandings of illnesses and conditions e.g. dementia and autism. These may be understood as a part of the natural life cycle or behavioural rather than a medical issue. A competing narrative can lead to a conflict when it comes to considering an appropriate response.

- There is a general **lack of trust in service providers**, particularly social services, to offer timely and appropriate support.
 - It is felt there are misplaced assumptions about the carer and their capacity to interact with services which leads to poor communication and decisions made without consultation.
 - There are also felt to be assumptions made regarding background, availability and willingness of individuals from minority ethnic background to be able to provide care. This means many feel they have little choice to do so, left to undertake care with less support and resources than carers from the wider population.

RECOMMENDATIONS

Having collected experiences and suggestions from unpaid carers, it is clear that this is a complex issue with multi-faceted, often overlapping issues that present barriers to accessing appropriate support. Therefore, any response needs to reflect this recognising that a 'one size fits all' solution is insufficient. The following are recommended actions and activities for Carers Trust, local authorities and the health and the social care sector more widely to consider:

Carers Trust

- Support Carers Trust Network Partners to collect ethnicity data as standard and monitor reach in comparison with local population prevalence
- Ensure lessons from successful services reaching carers from minority ethnic communities, funded under Making Carers Count, are captured and shared with the wider Network to encourage roll out

Carers Trust Wales

- Facilitate connections between carers organisations, organisations representing people from ethnic minority communities and local statutory partners to encourage the development of services tailored to the needs of unpaid carers from minority ethnic groups.
- Raise awareness of findings

Network Partner Organisations

- Consistently capture service users' demographic data, including ethnicity, and report on reach in comparison with the local population prevalence annually
- Consider alternative avenues and methods of advertising services and support. This includes identifying a variety of different locations and mediums used by different communities
- Proactively engage with organisations representing ethnic minority communities locally to partner in services tailored for minority ethnic carers
- Specific drive to recruit support staff from minority ethnic communities. This will not only encourage a change in attitude and understanding of available support, but also promote services and make them more attractive for others within the community who recognise it as appropriate to their needs

LOCAL AUTHORITIES, HEALTH BOARDS AND REGIONAL PARTNERSHIP BOARDS (RPBS)

Awareness raising

- Undertake a targeted and appropriate awareness raising campaign to change perceptions of the role of statutory social services. This includes increasing communication from service providers in terms of support available, entitlements, what can and cannot be expected from providers and clear communication as to how decisions are reached
- When services are culturally appropriate, ensure this is widely promoted, using appropriate language and terminology, to encourage awareness and take up
- Work with influential people within communities, such as faith leaders, to raise awareness and promote understanding and acceptance of different disabilities, conditions, the role of the carer and the positive aspects of seeking support

Communication

- Offer information in a variety of different languages during routine communications. In advance of meetings and appointments, make sure necessary translation services are available and allow sufficient time and space for information to be understood

Planning

- Ensure a person-centred approach to the organisation of service provision and support. Where possible, be flexible and innovative to different patterns of care that best suit the needs of both the individual in need of care and the person who cares for them
- In commissioning services, ensure they include meeting the needs of minority groups
- Consider a central point, accessible at the heart of the community, to provide all information regarding unpaid care

WELSH GOVERNMENT

- Ensure findings are considered by working groups delivering the Welsh Government Anti-racist Wales action plan and strategy for unpaid carers