

# MECOPP Response Scottish Government Consultation Proposed Carers Legislation April 2014

## 1. Information on MECOPP (Minority Ethnic Carers of Older People Project)

- 1.1 MECOPP was established in January 2000 as an independent Charity. The organisation assists Black and Minority Ethnic (BME) carers access the supports and services necessary to undertake or sustain a caring role. MECOPP currently supports in excess of 750 carers including carers within the Gypsy/Traveller community.
- 1.2 MECOPP, as one of the National Carer Organisations (NCO's) has contributed to the joint submission. Our individual submission will therefore concentrate on issues which may impact on BME carers specifically

## 2. Background Information

- 2.1 Figures on the number of BME carers in Scotland from the 2011 Census are currently not available. Reliance on the 2001 figures which record the total number of BME carers in Scotland as 6,815 can only give a broad indication given the time that has elapsed and concerns over under-enumeration. Given that the size of the BME population has increased quite markedly over the last decade, it is reasonable to assume that the number of BME carers will also have increased.
- 2.2 A summary of the issues affecting BME carers, based on existing research, has been produced by MECOPP and is available on the MECOPP website at <a href="http://www.mecopp.org.uk/resources.php?section\_id=5">http://www.mecopp.org.uk/resources.php?section\_id=5</a>.

### Key points:

- evidence<sup>1</sup> suggests that whilst the overall size of the BME carer population may be smaller due to a younger age structure, caring may start earlier than in the White majority population. Support for this argument may be found in the earlier onset of age related conditions as well as the genetic predisposition towards certain conditions that may be found in BME populations. This, in turn, suggests that BME carers may care for longer.
- o Research conducted by Carers UK<sup>2</sup> also identifies that BME carers are more likely to be caring for a sick or disabled child and in particular, an adult son or daughter aged between 20 24 years, which reflects longterm and enduring caring responsibilities. Overall, this suggests that

<sup>&</sup>lt;sup>1</sup> Netto, G (1996) 'No one asked me before'. Scottish Ethnic Minorities Research Unit/MECOPP

<sup>&</sup>lt;sup>2</sup> Carers UK (2012) Half a million voices: Improving Support for BAME carers

Minority Ethnic carers spend longer caring than other carers. The research also highlighted that BME carers are significantly more likely to be providing between 20 – 49 hours of care per week than their White counterparts.

- o Research commissioned by Carers UK³ similarly found that young South Asian women were more likely to be informal carers between the ages of 16 30 although this difference became less marked between different ethnic groups in the 30 59 age range and upwards. The research also found that amongst men of working age, defined in this instance as between 16 30, young South Asian men were two and a half times more likely to be carers than young White males. This was true of young men in both the Bangladeshi and Pakistani communities whereas young Chinese males were the least likely to be carers.
- o In Netto's study and others<sup>4</sup>, many of the findings refute common preconceptions associated with family structures and dynamics within Minority Ethnic communities. The belief in the 'extended family' as a primary source of support is not consistent with the reality reported by Minority Ethnic carers. For example, Netto found that 47% of respondents received no time off from caring, 44% of those in receipt of care were looked after by a sole carer and 69% had little or no family support. The reliance on one member of the family to provide care with little or no assistance from other family members, even in times of crisis, must question the veracity of such assumptions.
- A study conducted by Bowes and Dar<sup>5</sup> reinforced earlier findings<sup>6</sup> that deficiencies in service provision continue to be widely acknowledged by practitioners and policy makers alike.
- 2.3 The move towards 'shifting the balance of care' to the home and community will mean that family members, relatives and friends will play an increasingly central role in the provision of care, support and treatment for people who are frail, disabled or living with longterm conditions and illnesses. This will impact equally on BME carers as much as carers within the majority population. Yet, it is recognised that support services both within the statutory and voluntary sectors have consistently failed (with some notable examples of good practice) to provide adequate and appropriate support to BME carers. We therefore welcome the proposed legislation to provide more robust and consistent support to carers.

<sup>3</sup> Yeandle S, Bennett C, Buckner L, Fry G & Price C (2007) Diversity in Caring: towards equality for carers University of Leeds 4 Hubert J (2006) Family carers' views of services for people with learning disabilities from Black and Minority Ethnic groups: a qualitative study of 30 families in a south London borough, Disability and Society, 21, 3, 259-272. London: Routledge 5 Bowes, A M and Dar, N (2000) Family Support and Community Care: A Study of South Asian Older People. Scottish Executive

<sup>&</sup>lt;sup>6</sup> McCluskey, J (1991) *Ethnic Minorities and the Social Work Service in Glasgow* in Bowes, A M & Sim, D F (eds) Demands and Constraints: Ethnic Minorities and Social Services in Scotland. Edinburgh: Scottish Council for Voluntary Organisations

### 3. Carers Support Plan

- 3.1 Consultation with our service users supports the proposed change of name to a 'Carers Support Plan' to more accurately reflect the purpose of any 'assessment of need'. As a organisation, MECOPP concurs with this but we believe that more robust action is needed to ensure that local authorities (and any devolvement of the assessment process to third sector organisations) must be 'fit for purpose' for Minority communities. We therefore strongly advocate that all 'assessment' processes must adopt a 'culturally competent' approach. Failure to do so will only reinforce the current disadvantage experienced by Minority Ethnic carers.
- 3.2 MECOPP also supports the proposal to remove the 'regular and substantial' criteria believing that it is the impact of caring which should be the foremost consideration rather than the number of hours spent caring. We believe that this is particularly important for carers who struggle to combine paid employment or education with informal caring. This has particular resonance within Minority Ethnic communities where the predominant pattern of employment is within small and medium sized enterprises in retail and catering. Research conducted by MECOPP highlights that these enterprises are economically much less resilient that larger businesses and may struggle to support informal carers within the workforce. Having access to support and services externally may support carers to remain economically active, relieve isolation and improve their overall health and wellbeing.
- 3.3 We also welcome the proposed Duty on local authorities to inform carers of their entitlement to a carers support plan as this removes responsibility from the carer:
  - "If you do not know what you are entitled to, you cannot ask." (Chinese carer)
  - However, this Duty should be extended to acute NHS services and to the new integrated primary health and social care services.
- 3.4 We welcome the separation of the carers support plan from the community care assessment of the cared for. We believe that the current system which requires the person being cared for to be in receipt of community care or children's services is to the significant disadvantage of the carer. For many Minority Ethnic carers, this additional 'hurdle' can be 'one barrier too many' and prevent them from seeking support in their own right.
- 3.5 MECOPP agrees that the local authority in which the carer resides (if different from that of the cared for) should have responsibility for informing and completing the carers support plan. Our experience of working with individual practitioners and services alike demonstrates that many still hold the belief that Minority Ethnic communities are immune from demographic changes. We believe that this proposal is a practical response to changing family structures which may also assist in challenging these deeply embedded 'myths'.

### 4. Duty to provide advice and information

- 4.1 MECOPP supports the proposed Duty on local authorities to provide advice and information to carers although we have a concern that local authorities may choose to provide this in-house as a 'cost cutting' measure. As a 'specialist' organisation, we have developed a range of skills and experience in information provision which we do not believe will be replicated amongst local authorities. We are concerned that if taken in-house, information and advice to Minority Ethnic carers will be reliant upon interpreters and translators who do not have the necessary in-depth knowledge of carer's issues. We strongly advocate that the preferences of carers regarding the provision of advice and information should be at the heart of any decision making process.
- 4.2 We do not support the removal of the requirement placed on health boards to produce a carers information strategy (CIS). We believe that the development and implementation of the strategies has both highlighted carer's issues within health boards and added considerably to the availability of support services. However, there is still much to be done to challenge 'institutional blindness' of carer's issues and we believe the removal of the CIS would be a retrograde step.

# 5. Duty to support carers

- 5.1 MECOPP warmly welcomes the proposed Duties on local authorities to provide support to carers and young carers and to promote and provide short breaks. We believe that the provision of support (subject to identified need and an eligibility framework) will encourage carers to come forward and undertake a carers support plan. The current system whereby the local authority does not have a Duty to support carers following a carers assessment is counter-productive.
- 5.2 However, we have concerns that Minority Ethnic carers will still face considerable disadvantage irrespective of the proposed Duty to support carers as the overwhelming majority of mainstream services continue to prove inaccessible. Although self-directed support has the potential to increase support to Minority Ethnic carers, we are concerned that direct payments may become the default position of local authorities who may struggle to meet their needs within mainstream provision.
- 5.3 We have similar concerns about the promotion and provision of short breaks services by local authorities. Our experience demonstrates that BME carers have much lower levels of access to these services due to problems of accessibility and appropriateness. We would urge the Scottish Government to include with the proposed Short Breaks Statement, a requirement for local authorities to stipulate how they will meet the needs of Minority Ethnic carers.
- 5.4 In local authority areas where there is no BME carer support infrastructure, we believe that these problems will be particularly acute and will require a strong 'steer' from the Scottish Government.

#### 6. Carer Involvement

- 6.1 We support the proposal to require integrated and non-integrated bodies to include carers in the planning, shaping and delivery of services. We believe it is important that carers and people who use services are involved in determining the types of support and services that should be available in their community. We would argue that local authorities need to adopt a more proactive approach to involve BME carers as services based on the norms and values of the majority population will not necessarily be appropriate for BME carers.
- 6.2 We would place the same stipulations on local authorities with regard to the involvement of BME carers in informing and influencing local carer strategies.

#### 7. Carer Identification

7.1 We urge the Scottish Government to consider placing a Duty on GP practices via the GP core contract to develop a carers register and for GP practices to actively support carers within the practice. We believe that this will be particularly beneficial for BME carers who are unlikely to approach social work services in the first instance.

#### 8. Hospital Discharge

- 8.1 We support the proposal from the NCO's to place a new Duty on Health Boards with regard to the active involvement of carers within the hospital discharge process. Despite an existing Scottish Government protocol, practice across Scotland is 'patchy' at best. Work conducted by MECOPP highlights the specific problems faced by BME carers with regard to hospital discharge:
  - lack of knowledge about hospital discharge procedures and in particular, the right of the carer to an assessment of need;
  - lack of overall involvement in the hospital discharge process;
  - fear of challenging medical professionals;
  - lack of understanding on the part of practitioners to adequately take into account specific cultural needs; and,
  - failure to adequately signpost BME carers and those in receipt of care to appropriate support agencies on discharge.