Carers (Scotland) Bill Stage 1

MECOPP (Minority Ethnic Carers of Older People Project)

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, and fully endorses, the joint NCO submission. Our individual submission will therefore concentrate on issues which impact on BME carers specifically and carers with protected characteristics more generally.

1.3 MECOPP welcomes the main provisions of the Bill but would argue that all measures contained should be strengthened by the inclusion of an equal opportunities clause as permitted by Part 11, Schedule 5 of the Scotland Act (1998). This clause enables the Scottish Parliament to place a duty on devolved public authorities to ensure functions are taken forward with due regard to equal opportunities.

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MECOPP is asking for an equal opportunities clause to be included on the face of the Bill. In subsequent regulations and guidance we ask that local authorities be required to produce an equal opportunities statement and action plan setting out how they intend to meet the needs of carers with one or more of the protected characteristics.

We ask that the statement and action plan is published as part of the local carer strategy and subjected to rigorous monitoring of, and reporting to, the Scottish Government

Evidence of the process followed in developing the Statement and the action plan should also be included.

1.4 MECOPP would also advocate that the Bill must pay due regard to international human rights and the obligations that exist as a State signatory to the International Covenant of Economic, Social and Cultural Rights (ICESCR). Given the substantial body of research which evidences the disproportionate negative impact on the physical, emotional and financial health of carers, we believe the Bill should consider how it can support the attainment of:

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1 The nine protected characteristics under the Equality Act (2010) are race, age, disability, gender reassignment, religion & belief, sex, sexual orientation, marriage and civil partnership and pregnancy and maternity.
the right of everyone to an adequate standard of living, and to the continuous improvement of living conditions (Art 11)

the right of everyone to the enjoyment of the highest attainable standard of physical and mental health (Art 12)

2. BME Carers in Scotland

2.1 According to the 2011 Census, Scotland’s Black and Minority Ethnic (BME) population has doubled in the last decade (2001 – 2011) growing from 101,677 (2.01%) to 210,996 (4%).

Similar growth in the size of the BME carer population over the same period is also evident rising from 6,815 to 12,049. However, despite the substantial increase in the number of individual BME carers, as a percentage of the total BME population, there has been a slight decrease from 6.7% in 2001 to 5.7% in 2011. The key point is that every local authority in Scotland has seen a sizeable increase in the size of its BME carer population. Within individual ethnic groups, the largest increases are to be found in the Pakistani, Chinese and African populations in Scotland.

Analysis of Census information also indicates that the largest cohorts of carers within individual ethnic groups are to be found at the lower (1-19 hours caring per week) and highest (50+ hours of caring per week) points in the spectrum.

2.2 Information on the number of carers within the Gypsy/Traveller population can also be taken from the 2011 Census for the first time. The Census records the size of the Gypsy/Traveller population as 4,212 but community members and organisations working directly with the community estimate the population to be closer to 20,000. Given the sizeable discrepancy, we believe that the size of the Gypsy/Traveller carer population is also significantly under-enumerated at 10% (although this compares with 6.9% of the general population).

2.3 Research conducted by MECOPP into the experiences of Gypsy/Traveller carers found that access to social care services was “at best problematic, at worst non-existent”. There was limited knowledge of individual rights and relationships with social care workers were characterised by a lack of trust. The research concluded that care services are “often ill-suited to the cohesive and private nature of the Gypsy/Traveller community.” These findings were echoed in 2012 by the Scottish Parliament Equal Opportunities Committee who found Gypsy/Travellers’ experiences of health and

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2 2011 Census
4 MECOPP, 2012, Hidden Carers, Unheard Voices: Informal Caring within the Gypsy/Traveller Community in Scotland
5 Ibid
social care to be “appalling”, “concerning” and “alarming”. They stated that a lack of cultural competency amongst service providers was a major barrier in ensuring that carers receive the support they need: “It is clear to us that one of the greatest barriers to supporting Gypsy/Travellers ... is a lack of understanding about their lifestyle, population and travelling patterns”.

3 Carers with Other Protected Characteristics

3.1 Whilst informal caring in itself does not constitute a ‘protected characteristic’ under the Equality Act (2010), individuals with protected characteristics are as likely to assume a caring role during their lifetime as the rest of the population.

3.2 Gender

3.2.1 Figures provided by the Scottish Government highlight that women of working age are more likely to take on a caring role. 62% of carers between the ages of 25 – 49 are female. Given the heavily gendered bias, we welcome the strong Government focus on gender equality outlined by the First Minister. A key concern must be how the Bill will support women who are already experiencing a ‘carer penalty’ alongside more general concerns about the progression and status of women within the labour market.

3.3 LGBT Carers

3.3.1 In addition to the challenges which all carers experience, we would argue that informal carers within LGBT (lesbian, gay, bi-sexual and transgender) communities can face additional barriers at all levels of the social care system. Informal care is very often, part and parcel of a wider network of support which can include health and social work professionals as well as services such as homecare, short breaks provision and longer term residential care. Yet the fear or actuality of homophobia and other forms of victimisation can and do prevent informal carers from seeking support and accessing services.

3.3.2 For the vast majority of people with limiting long-term conditions or disability, the family remains the primary source of support both emotionally and practically. Yet for many older LGBT individuals, these choices may be limited. They may not have children or grandchildren and may be isolated from their family of origin. Older LGBT people may be forced into concealing their sexual/gender identity for fear of harassment and discrimination within services.

"We were treated differently to heterosexual couples who meet in a private space during visiting times whereas we had to meet in the

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6 http://www.scottish.parliament.uk/parliamentarybusiness/CurrentCommittees/54885.aspx
7 Scottish Parliament Equal Opportunities Committee, 2012, Gypsy/Travellers and Care
dining room of the hospital ward. One day when I put my arm around Martin to comfort him I was told to stop by healthcare staff as they thought this may lead to ‘other things.’ As a very private person I was extremely upset and humiliated.”

3.4 Disabled Carers

3.4.1 No information currently exists on the number of disabled people or individuals with a long-term condition who provide informal care. We believe it is reasonable to assume that this cohort is sizeable and will continue to grow as the population ages and individuals enter into co-caring relationships. Similarly, people with learning disabilities may take on caring responsibilities for elderly parents.

4 Comments on the Bill

4.1 Despite a legal obligation to ‘advance equality of opportunity’\textsuperscript{11} for individuals with one or more of the protected characteristics, there is substantial evidence regarding differential levels of access to services for carers from minority groups including carers from Black and Minority Ethnic communities\textsuperscript{12}, LGBT carers and disabled carers. Despite commitments within ‘Caring Together’ to ensure actions are taken forward with due regard to “fully address the equalities perspective”, this has not been evident across local authorities and health boards in Scotland. Whilst ‘pockets’ of good practice exist, MECOPP believes it is time for a more concerted effort to focus the attention of local authorities and health boards on meeting the needs of carers with protected characteristics. We believe the inclusion of an equalities clause on the face of the Bill will make these expectations explicit.

4.2 Part 1 – Duty to prepare Adult Carer Support Plan

4.2.1 MECOPP welcomes the Duty to prepare adult carer support plans but would argue that this section needs to be strengthened. As the Bill currently stands, the proposed Duty only applies where the local authority has made an offer and that offer is accepted or where the carer has requested a plan. We believe that a Duty should be placed on local authorities to inform carers of their right to an adult carer support plan.

In a practitioner survey conducted jointly by MECOPP and Carers Scotland to inform the development of the Carers Rights Charter, 60% of respondents indicated that disabled carers or carers with a long-term condition were less likely to know about their rights with this

\textsuperscript{10} Caring Together: The Carers Strategy for Scotland 2010-2015 Scottish Government 2010

\textsuperscript{11} The General Duties under the Equality Act (2010) are to: eliminate unlawful discrimination, harassment and victimisation and other prohibited conduct; advance equality of opportunity between people who share a relevant protected characteristic and those who do not; and, foster good relations between people who share a protected characteristic and those who do not.

\textsuperscript{12} http://www.mecopp.org.uk/resources.php?section_id=5
percentage increasing to 89% and 100% for LGBT and BME carers respectively\textsuperscript{13}. Without a Duty to inform, we believe the current situation will continue to the detriment of carers with a protected characteristic.

4.3 **Adult Carers - Identification of outcomes and need for support (section 7)**

4.3.1 The focus within the Bill on enabling carers to achieve personal outcomes is welcome but as currently stated within the Bill, too narrowly defined. We believe that the emphasis needs to be changed from ‘inputs’ that enable a carer to provide or continue to provide care to outcomes which reflect their status as citizens who are entitled to a life outside of caring. We argue that supporting carers to identify and achieve personal outcomes must be consistent with a human rights based approach grounded in dignity, autonomy and choice.

We raise an additional concern that achieving personal outcomes for carers with a protected characteristic may be further constrained by the lack of appropriate and accessible services both for themselves and the person they care for.

4.4 **Content of adult carer support plan (section 8)**

4.4.1 MECOPP has consistently argued that any assessment of need should be ‘culturally competent’ recognising that the nature and extent of care delivered by minority groups may differ from the majority population. As the adult carers support plan will be used to determine eligibility for services, we believe it is even more important that the assessment process is fit for purpose.

For example, the Scottish Parliament Equal Opportunities Committee inquiry into Gypsy/Travellers and Care noted:

“It was clear that cultural sensitivities might be overlooked when providing care for Gypsy/Travellers ... We were shocked to hear of Gypsy/Travellers feeling that they had no choice other than to settle in housing away from their own communities to access care services”\textsuperscript{14}

4.5 **Part 3 - Provision of support to carers - Eligibility Criteria**

4.5.1 MECOPP fully endorses the NCO position that a national eligibility framework should replace local eligibility criteria. We believe this offers more scope to embed equality outcomes as part of the overall approach. Concerns are already apparent regarding the imposition of local eligibility criteria in the implementation of the Social Care (Self


\textsuperscript{14} Scottish Parliament Equal Opportunities Committee, 3\textsuperscript{rd} report, 2012 (session 4), Gypsy/Travellers and Care.
Directed Support) (Scotland) Act 2013\(^\text{15}\) and we are keen that this is not repeated.

4.5.2 With regard to the setting of local eligibility criteria, we have significant concerns that they will disadvantage carers with protected characteristics. Whilst the Duty to consult is welcome, we would extend the scope of consultee’s to include organisations which support individuals with protected characteristics where there is no carer specific support. Without this, we believe that the needs of carers with protected characteristics will continue to be invisible from local decision making.

If local eligibility criteria are to be set, we argue that they should be consistent with local equality outcomes.

4.6 Duty to provide support to carers (section 22)

4.6.1 MECOPP welcomes the Duty to be placed on local authorities and health boards to support carers but would strongly argue that the Duty is only as effective as the services that are available to meet the assessed need. Without appropriate and accessible services, the Duty is, at best, ineffectual in supporting carers with protected characteristics.

As it currently stands, the duty to support carers will only apply where their needs cannot be met

“…by services or assistance provided \textit{generally} to persons in the area of the responsible local authority”

MECOPP has interpreted this (ie. \textit{general} support) to mean support which is available universally within the local community and which does not require any form of assessment or eligibility criteria.

The Bill does not define which services are ‘general’ but the Policy Memorandum describes eligible services as ‘bespoke services’ and states:

“\textit{Bespoke support would include, for example, short breaks, training, advocacy and emotional support}” (Page 22 paragraph 92)

We know from our own experience that many of the services described as ‘bespoke’ are, in fact, provided by carer organisations as part of a package of universal support and would include access to training or emotional support. We feel the terminology is unhelpful in this respect and potentially confusing but have a more deep rooted concern that this provision will work against the best interests of carers with a protected characteristic.
4.6.2 Having worked with BME carers for nearly 20 years, MECOPP is well placed to comment on the historical ‘suspicion’ held by the communities we work with in relation to social work services. Many of the services we currently provide to our beneficiaries would now be seen as ‘bespoke’ services as defined in the policy memorandum and subject to an assessment. Assessment processes are, at best, problematic for BME carers due to the marked lack of confidence in the ability and capacity of mainstream providers to respond. Having to undergo an assessment for services that were previously available with no restrictions is yet another barrier.

MECOPP endorses the NCO position that all carers should be able to access universal services (e.g. carer training, advocacy, emotional and peer support) which are freely available to all carers.

4.6.3 The implementation of self-directed support with its focus on choice and control, on the face of it, provides carers with a protected characteristic (and those they care for) with an opportunity to acquire the support they need in the manner they require. However, we raise a broader concern that SDS and in particular, option 1, does not absolve local authorities and other bodies covered by the Equality Act (2010) of their legal duty to ensure that their services are accessible to all sections of the population. We are concerned that SDS may become the default position of local authorities who cannot meet the needs of minority communities within mainstream provision.

4.7 Part 4 & 5 – Carer involvement (section 25) & local carer strategies (section 28)

4.7.1 The Duty to involve carers in carers’ services and the development of local carer strategies is again welcomed but we have similar concerns regarding the exclusion by default of carers with protected characteristics (see 4.5). Any assessment of unmet need should actively consider the needs of carers with one or more of the protected characteristics.

4.8 Part 6 - Information and advice for carers

4.8.1 We welcome the focus on the provision of advice and information for carers as an integral element of informed decision making but would stress that such provision must take account of the communication, linguistic and cultural requirements of the intended audience. In many cases this will be a requirement of the Equality Act (2010), for example, the provision of BSL.

MECOPP