

Reference to PRIAE, pg 2

<http://www.publications.parliament.uk/pa/ld201213/ldhansrd/text/130110-0001.htm>

Disability Services

Over-looked Communities, Over-due Change, Motion to Take Note

12.33 pm

Moved By Lord Boateng

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1.40 pm

Lord Ouseley: My Lords, I thank the noble Lord, Lord Boateng, for introducing this debate and giving us the opportunity to consider the excellent Scope report and the issues contained in it, and bring them before the House to enable the Minister to respond. I also thank him for enabling us to pick up on any other related issues in the area of disabilities as they affect black and minority ethnic communities.

The challenge facing policymakers and decision-makers is to understand the multiple disadvantages being faced by black and minority ethnic disabled people, and to collaborate with community-based and community-led organisations to determine appropriate and effective responses. Following on from what the noble Lord, Lord Addington, had to say, this resonates well with how we involve people who are able to relate to those who have needs and how we help them to respond to these needs at the earliest opportunity.

Where available, the data show black and minority ethnic people having disproportionate adverse experiences of access to income, education and essential support services, in the job market and in utilising public facilities. When we add the disability characteristics, we find that the situation is considerably worse. Increasing numbers of BME disabled people are experiencing discrimination and disadvantages because of a combination of factors, including race, ethnicity, class, poverty, status and where they live. The latter is an important discriminatory feature that we must also consider.

The wide range of disabilities requires appropriate responses, whether the disabilities exist from birth, develop through disease or injury, or occur because of ageing and infirmity. My contribution is particularly concerned with two areas of disability. The first is that which is due to ageing and infirmity. The second regards mental illness. As they advance in age, more BME people are experiencing many forms of disability and impairment. My mother, who is 85 years old, disabled and bed-bound, is in the fortunate position of having care provided for her on a 24/7 basis. My siblings and I are able to make that provision without recourse to external involvement. However, many people are unable to experience that support. Many like her, with similar afflictions and who may not be able to obtain the same level of support, will more likely than not experience a diminishing quality of life in their latter years.

Quality of life and quality of care are essential components of growing old with dignity. As a society

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we are currently grappling to find solutions to the cost implications of making appropriate provision for the care needs of a growing elderly population with multiple impairments and disabilities. I have worked in old people's and adult care homes with people with severe conditions, and I pay tribute to those who are carers. Occasionally we hear stories of where people have been let down by standards of care but on the whole we see in this situation committed and dedicated people helping others, whether in a professional capacity or on a voluntary basis. In the context of today's debate it is important to acknowledge the work done by BME carers, both within the family setting and in voluntary self-help settings.

As the previous chair of an organisation called the Policy Research Institute on Ageing and Ethnicity, I had the benefit of observing at first hand for more than a decade the significant contribution of BME-led adult care organisations which reach out to BME elders across the country. Considerable work was done in outreach activities to make them aware of the increasing prevalence of dementia, so that the elders could be referred to services at the earlier stage of the condition. This work also addressed their multiple and complex health needs.

This is a good moment to remind the noble Lord, Lord Boateng, that he was involved in helping to launch a study with PRIAE in 1999, *Managing Dementia and Ethnicity*, which resulted in a film called "Dementia Matters". The study has been distributed widely among educators and people in the profession.

Without minority ethnic, age or specialist organisations that cater for such groups directly, BME elders with disabilities would remain invisible and, worse, would still not be supported. The challenge for mainstream organisations, including large equality ones, is whether they are prepared to engage with and invest in minority initiatives and organisations. BME communities are part of British society. BME elders with disabilities are British, yet we see the dangers of parallel but unequal services developing, with different organisational resources, funding, capabilities and life spans.

That trend is even more accentuated in the area of BME mental health sufferers. Undoubtedly, in the area of mental health disability there are outrageous disparities. For example, the life expectancy of people from the UK's African-Caribbean communities who come into contact with services under the Mental Health Act is reduced by a staggering 25 years, as they are routinely labelled schizophrenic or psychotic. Early intervention and culturally appropriate services remain at best sparse and at worst non-existent. There is an extensive body of evidence cited by Black Mental Health UK that indicates that the UK's African-Caribbean communities are subject to the most coercive and punitive treatment, often with fatal consequences.

Deaths in custody and reduced life expectancy have blighted many African-Caribbean households. It is known that more than 50% of those who lose their lives in police custody are mental health service clients. The same data from the Equality and Human Rights Commission reveal that 20% of deaths in police custody involve black men, who represent less than 3% of the national population.

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What is being done to safeguard BME disabled rights? Effective advocacy provision, particularly led by BME organisations, would be an essential requirement to assist in achieving fairness; this at present is lacking. Individuals being treated under the Mental Health Act, whether in hospital or in the community, have the right to access an independent mental health advocate to ensure that their rights are observed and that they are treated fairly. Black patients in detained settings do not have access to effective advocacy. In far too many cases, they are not even informed of this right.

Black Mental Health UK is deeply concerned about the effects of treatment to BME disabled people with mental health illnesses. Black people presented to the service are routinely labelled as psychotic and given high doses of anti-psychotic medication, which come with a raft of side effects that include irregular heartbeat, cardiac arrest, muscle and joint pain, jerkiness similar to the symptoms of Parkinson's disease, severe sexual dysfunction, rapid weight gain, obesity, diabetes, heart disease and reduced life expectancy. These matters must be addressed as part of any overall strategy, and within the particular context of mental health.

I will raise one final concern: the presence of police, often in riot gear, on psychiatric wards. High-profile death in custody cases have reinforced distrust both of the police and of mental health services. It is necessary that there should be a consistent mechanism for monitoring deaths that occur after police restraint on psychiatric wards. Only in cases where there is a high-profile fatality and the family are vocal about the incident are such matters brought to public attention. It is right that the Minister should respond and say how we will seek to share information in an open and accountable way that will enable those who provide support services for those with mental health illnesses to be made aware of how they can contribute to ensuring that the latter's rights are safeguarded.