The Work of Care\textsuperscript{1}

Report of the Political Studies Association (PSA) Commission on Care

Evidence Gathering Day

11\textsuperscript{th} March 2016

St Michael’s House

Coventry

The PSA Commission on Care met in Coventry on 11\textsuperscript{th} March, 2016 to gather evidence from paid and unpaid workers and their representatives within the social care sector on the impact of austerity on the care of older people. Three roundtables covered different aspects of care work. The programme started with testimonies provided by care workers, and from UNISON (Coventry City branch) on the adverse staffing effects of council budget cuts. Dr Shereen Hussein from King’s College, London gave a keynote talk on the social-care workforce challenges in times of political and economic instability. The afternoon sessions centred on the importance of organisations such as The Alzheimer’s Society in providing information and support to carers. The event concluded by exploring the particular and growing challenges that BAME carers face and the strategies to support them to address complex health needs in times of austerity.

\textsuperscript{1} This report has been written by Keira Koroma, a Warwick University MA student and student research assistant to the PSA Commission on Care.
The full-day event was chaired by Belinda Phipps (Chair, Fawcett Society) and attended by the members of the Commission – Prof. Ruth Pearson, Prof. Shirin Rai, Dr. Juanita Elias and Dr. Daniela Tepe-Belfrage. The event also involved care workers, union representatives, representatives of organizations delivering care and support within BAME communities, other organizations working with carers, informal carers, academic researchers alongside members of the public.

A key theme to emerge from the first part of the day was that paid carers are concerned about the increased uncertainty surrounding their jobs as the result of concerns about future local government funding. In addition, older people being cared for feel anxious and often worry about whether their care home or access to domiciliary care will be impacted by funding cuts. For older people living in council-run homes and/or supported accommodation, these concerns are particularly acute given the declining role of local authorities in the direct provision of care accommodation. The commissioners heard from workers employed within Coventry City Council care facilities under threat of closure. They expressed concerns for those in their care, emphasising: ‘that for some of these people it’s their last home’ and that ‘they don’t want to be moved again’. This speaks to previous research that suggests that there is a tragic correlation between older people in care being moved and mortality.

When asked what they felt were the more challenging aspects of their work, one of the care workers highlighted the increased integration of people with a variety of needs such as alcoholism within the care homes. Although the carers did not feel physically threatened, they often felt that dealing with alcohol related abuse was difficult to bear; on some occasions younger patients ‘played off’ staff against the older clients. It was suggested that such integration of care is increasing as Coventry City Council is rapidly withdrawing from direct care provision and outsourcing it to generalised providers.

Travelling to work and between places of work was highlighted as a further key challenge – and a particular problem within the domiciliary care sector. It was noted that as a result of cutbacks and the introduction of city-wide contracts for home support providers, travelling to work had increased without monetary compensation for potential increases in travel time or transportation costs. It was noted that city-wide contracts do not cover ‘mileage for care workers travelling in their own car; they and also don’t get paid for their travel time’. As a result, it was difficult for the carers to do anything but the bare minimum for the care recipient: ‘if [we are] allocated to put them [the clients] to bed, then [we] could be putting them to bed at 8pm and then nobody comes back to get put them up till 9am the next day’, said a carer.

UNISON (Coventry City branch) described that members were increasingly finding it harder ‘to be flexible’; hence staff had to take ‘unpaid holidays to provide external care to [their own] family members’. It was suggested that a form of government intervention was needed to standardise the levels of private care. The UNISON (Coventry City branch) representative commented that UNISON
has an ethical charter (https://www.unison.org.uk/content/uploads/2013/11/On-line-Catalogue220142.pdf) that it is encouraging good employers to sign up to. However, because the implementation of such policies affect companies’ profits they are not widely supported by employers.

Dr Hussein’s (King’s College London) keynote talk highlighted her research finding that one of the leading causes for care-workers entering the sector was a desire to ‘help’ and passion towards ‘serving’ others. This supported the earlier statements made by the paid workers that they found their work satisfying and that they wanted to ‘do some good’. However, Dr Hussein also highlighted the fact that that care-workers were in the ‘amber/red’ zone of psychological work stress. Moreover female carers preferred not to take on supervisory positions as they felt that the minimal increase of pay did not compensate for the increased responsibility and duties. Dr Hussein outlined the leading causes of carers resigning from their jobs: insecurity, lack of job progression and work-based stress. Finally, Dr Hussein’s research showed the imbalance between the aging population demographic, the decreasing central government contributions’ to Local Authorities and the decreasing care sector workforce; this showed a ‘worrying’ care trend (Dr. Hussein’s presentation can be accessed here: http://www.kcl.ac.uk/sspp/policy-institute/scwru/pubs/2016/conf/hussein11mar16.pdf).

In the Q&A that followed Dr. Hussein’s talk, informal carers felt that their experiences were not fully represented in much of the existing research and policy studies. A carer wondered whether anyone actually knew that she cared for her mother and felt that her experience as an ‘invisible’ carer was not unique. It was also suggested that employers are often uninformed about the obligations towards people who also provide unpaid care mandated in the Care Act 2014, such as the assessment of their needs as carers. At the same time, informal carers felt ‘worried’ about declaring their status as a carer to their own employers.

David Truswell (Chair, Culture Dementia UK) commented on the broad demographic shifts in the UK’s ageing population that were emphasised in Dr. Hussein’s presentation – namely the significant increase in the black, Asian and minority ethnic (BAME) proportion of the older population over the next fifty years. He emphasised that such demographic shifts will lead to increasing challenges and complexities for those delivering care to older people. He observed that often those who ‘have dementia don’t just have that, they also have something else […]like high blood pressure.’ In Truswell’s experience, those who suffer from dementia within the BAME community often go for a long time without being diagnosed due to the stigma of the condition. In effect, when diagnosed they are already suffering from a multitude of medical conditions. For many BAME people who migrated to the UK in the 1960s and 1970s there are particular challenges associated with changing family dynamics including the composition and location of families as well as the psychological impacts of having to rethink plans to return ‘home’ in older age.
Within the Q&A it became apparent that although the Care Act 2014 requires Local Authorities to provide assessments and information about care services, it doesn’t require that they directly provide care. Dr Hussein noted that the provision of care often fell on charitable organisations, which meant that if there was not a local branch of a care providing charity in one’s area then finding care provision became a serious problem for the person requiring care. This situation is particularly difficult when the person responsible for organising the care is a relative living in another part of the country.

In the afternoon session we heard from a Dementia Navigator and an informal carer who both work with the Alzheimer’s Society Coventry. They spoke about the work of the Society and caring for older people with the condition. The audience also heard the moving testimony of the carer’s experience caring for her mother who had dementia. She spoke of her feelings of the unfairness of the situation, coupled with trying to balance taking care of her mother and her young children. Nevertheless, she felt happy and proud that she could ‘look back at giving back to [her] mother’. She also spoke of her sadness, as her mother’s health deteriorated, that after exploring multiple avenues of trying to manage her mother’s care at home she had to recognise that her mother needed to enter a care home: ‘the day Mum entered her new home will stay with me forever’. She explained her experience of that day as ‘feelings of immense guilt, sadness and wondering if we were doing the right thing’. Concluding, she said that it had been a ‘rollercoaster of a journey’ and that her advice for other carers would be to ‘seek help, lean on people whether it be family or friends and most importantly find time to laugh’.

Dr Carol Mockford, University of Warwick, presented 'The SHARED study' about caring for older people with memory loss after hospital discharge³, which was co-researched with former carers (Sue Boex, Yvonne Diment, Richard Grant and Uma Sharma) The lay researchers spoke about their experiences of conducting interviews and felt that they offered a unique perspective to the study because of their ‘lay-ness’. It was noted by the study that those interviewed felt a disconnect in communication between hospital staff and patients/their carers after they had left hospital care. This was suggested to be due in part because of the handing over process between hospital staff care and community support after patient release. The study noted that people were being treated like ‘cars in a factory [...] handed over to each section as if they were inanimate objects rather than people’.

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³ A study of the experiences of service provision from two NHS Trusts by older people with memory loss and their carers after a stay in hospital, and the development of service user led recommendations. (more information on the study can be found at this link https://www2.warwick.ac.uk/fac/med/research/hscience/rcn/research/themeb/nihrproject
The concluding session focused on the challenges that BAME carers face and strategies to support them. David Truswell, a leading figure in the work of care in BAME communities spoke about the care needs of the Afro-Caribbean community in England. Truswell emphasised that this community has significantly higher rates of dementia yet there is very little research on this topic. He further stressed that there is an urgent need to recognise that the increasing numbers of older people in the BAME community are likely to have complex needs. Truswell also spoke of the lack of cultural understanding of dementia and the propensity to not discuss it if ‘people are acting strangely’, leading to late diagnosis which results in a ‘chunk of resources’ being missed by the patient. It was emphasised that there is a need for a conversation about the processes of getting help and the complexity of the condition by organisations at the forefront of care of the BAME community such as the Alzheimer’s Society ‘Connecting Communities’ project. Nnanna Uwakwe (Project lead for the project based in Waltham Forest) supported Truswell’s statements and highlighted the importance of working within churches and with church leaders to change the cultural stigma of the symptoms of the disease and awareness of the support for BAME carers. Truswell also noted, however, that austerity-related cuts had also led to the defunding and disappearance of many of the community-level organisations that act to support migrant, especially new migrant, communities – for example, assisting them in locating care services and navigating the health care system.

The one-day event served as a safe space for informal and paid carers to speak about their experiences in the sector and, importantly, feel heard by the Commission. Through sharing their testimonials the discussion illuminated the increasing crisis of care evidently affected by cuts to local authorities’ budgets and to the sector as a whole. The evidence gathered through these discussions will prove invaluable to the work of the PSA Commission on Care.