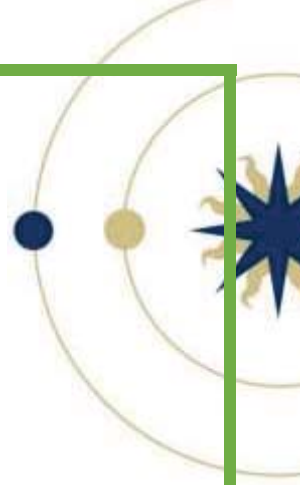




GREEN TEMPLETON COLLEGE | OXFORD



GREEN TEMPLETON COLLEGE

CARE INITIATIVE

Annual Report 2015-6

This report was compiled by Dr Sue Westwood

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INTRODUCTION

This report summarises the activities of the Green Templeton Care Initiative in the academic year 2015-2016. The Initiative is led by Professor Mary Daly, Department of Social Policy and Intervention and Governing Body Fellow, Green Templeton College, University of Oxford.

1. THE GREEN TEMPLETON CARE INITIATIVE

The Green Templeton College Care Initiative is oriented to exploring issues associated with the care of older people. The Initiative is intended to bring together people from different disciplinary and professional backgrounds to engage in informed debate and research regarding the complex issues involved in caring for and with older people. Its general aim is to raise debate and circulate knowledge about social care and also increase understanding of social care as a domain of social and health policy.

The aims of the Initiative are rooted in Green Templeton College's engagement with and commitment to human welfare as a foundational College interest and common concern. Membership of the Initiative reflects the disciplinary orientations of College, drawing together especially scholars and students from the medical sciences, the social sciences and the business and management divisions at Oxford. The Initiative is also active in engaging with people from the public service and NGO sectors in Oxford (as well as academics from other units in Oxford) and has been very successful in assembling a wide community of interest.

Activities centre around exploration of the wide-ranging issues associated with the challenge of caring in an increasingly ageing society. The Initiative's signature approach is to view these issues from a multi-faceted perspective, drawing together philosophical, institutional, resource and policy/service considerations. The topics that the Initiative has identified as key include: investments in and costs of social care; innovations in social and health care (with particular reference to online and digital, technological innovations); reimagining and remodelling care; philosophies of care and caring; and the degree to which physical, social and personal environments enable people to live out their lives in the place(s) which they consider home.

In its first year, the initiative held seven meetings. It was launched on Monday 27 October 2014 with a lecture by Sir Andrew Dilnot, Chair of the Commission on Funding of Care and Support. The following sub-themes were discussed in subsequent 'care conversations' over the course of the year: care and new technological developments; person-centred well-being and the changing model of service provision; the role of social infrastructure in creating a care-friendly environment; the impact of design of the physical environment on care provision; the current state of investment in social care markets.

2. 2015-16 SUMMARY

A new round of 'Care Conversations' took place in 2015-2016. A 'state of the art' interdisciplinary review of the literature on social care for older people in the UK was also undertaken, resulting in the report by Dr. Sue Westwood entitled 'Social Care and Older People in Home and Community Contexts: A Review of Existing Research and Evidence'. Professor Mary Daly and Dr Westwood have written an academic paper (submitted to a journal) based on findings from the review.

3. CARE CONVERSATIONS

Context

There are pressing issues and concerns in relation to older people and social care. With an ageing population, more people are living for longer, and into later old age. The oldest old often have multiple, chronic, and ongoing ill-health and disabilities necessitating support from others to maintain their daily living and personal care. The number of functionally disabled older people in England is projected to double from approximately 2.3 million in 2002 to approximately 4.6 million in 2041 (Commas-Herrera et al, 2006). In the United Kingdom (UK), the number of people with age-related dementia is forecast to increase to 1,142,677 by 2025 and 2,092,945 by 2051 (Prince et al, 2014).

Based on current models of health and social care provision in the UK, this ageing and dementia-related demographic has the following implications for health and social care provision:

- To keep pace with demographic pressures over the next 40 years, assuming unchanged rates of functional disability, residential and nursing home places would need to expand by around 115% and numbers of hours of home care by around 100%.
- The numbers of staff working in social care for older people would need to increase by around 110% between 2002 and 2041 to provide this increased level of services.
- Long-term care expenditure would need to rise by around 325% in real terms between 2002 and 2041 to meet demographic pressures and allow for real rises in care costs of 2% per year for both social care and health care.
- Long-term care expenditure would need to increase from 1.4% of GDP in 2002 to 2.6% of GDP in 2041 to meet demographic pressures, assuming annual increases in GDP in line with HM Treasury assumptions.

(Comass-Herrera et al, 2006, page 1).

In effect, there is an increasing gap between care needs and care expenditure. This is caused by increasing numbers of older people living for longer with high care and support needs at the same time as both informal and formal care resources are diminishing. Pickard predicts an imminent shortfall in informal social support for older people:

The supply of care to older people with disabilities by their adult children in England is unlikely to keep pace with demand in future... Demand for unpaid care will begin to exceed supply by 2017 and the unpaid 'care gap' will grow rapidly from then onwards. (Pickard, 2015, page 96).

There are growing concerns about rising unmet care needs in relation to older people (Vlachantoni et al, 2011; National Audit Office, 2014). The gatekeeping of formal service provision/funding is predicated upon notions of 'need' and in recent years only those with the greatest level of need have received formal support. Prior to the Care Act 2014, local authorities had discretion in setting their own thresholds, according to the four bands of need identified in policy, i.e. critical, substantial, moderate and low. Many local authorities were already only providing services and/or funding for 'substantial' and 'critical' assessed needs prior to the Care Act, within the wider context of an 'intensification' or targeting of council services to a smaller number of persons with the greatest need (Audit Commission, 2009). However since the

implementation of the Care Act 2014 local authorities are required to meet only 'substantial' and 'critical' care needs. This intensification has coincided with growing austerity measures and reduced funding for formal social care provision. Despite growing numbers of older people, in England a third fewer older people were receiving formal social care services in 2012/13, compared with 2005/6 (Fernandez, Snell & Wistow, 2013).

Recent research suggests that a growing number of older people have a wide range of needs which are now 'unmet' both in relation to daily living activities (Forder & Fernandez, 2015) and wider quality-of-life issues (Vlachantoni et al, 2011). According to Age UK, of the 2.8 million older people with care related needs, 900,000 currently do not receive any formal support (Age UK 2015). In Oxfordshire alone last year there were some 1,850 persons assessed as ineligible for care and support. There is at present a lack of knowledge about the consequences of these unmet needs for older people and their communities (Fernandez & Snell, 2012).

References

- Age UK (2015) *Later Life in the United Kingdom October 2015 Factsheet*, September 2015 update: http://www.ageuk.org.uk/Documents/EN-GB/Factsheets/Later_Life_UK_factsheet.pdf?dtrk=true
- Audit Commission. (2009). *The Financial Implications for Local Authorities of an Ageing Population: Policy and literature review*. London: The Audit Commission.
- Comas-Herrera, A., King, D., Malley, J., Pickard, L., Wittenberg, R., & Darton, R. (2006). *Thirty-five Years On: Future Demands for Long-term Care in England*. London: London School of Economics and Political Science (PSSRU).
- Fernández, J. L. & Snell, T. (2012) *Survey of Fair Access to Care Services: (FACS) assessment criteria among local authorities in England*. London: LSE, PSSRU.
- Fernandez, J. L., Snell, T., & Wistow, G. (2013). *Changes in the Patterns of Social Care Provision in England: 2005/6 to 2012/13*. Personal Social Services Research Unit PSSRU Discussion Paper 2867. Canterbury and London: University of Kent and London School of Economics.
- Forder, J. & Fernandez, J.L. (2015) *Using a 'Wellbeing' Cost Effectiveness Approach to Improve Resource Allocation in Social Care*. Discussion Paper 2893. Quality and Outcomes of Person-Centred Care Policy Unit. University of Kent, London School of Economics and University of Oxford. Available from: <http://eprints.lse.ac.uk/61221/>
- National Audit Office (2014) *Adult Social Care in England: Overview*. London: The Stationary Office.
- Pickard, L. (2015). A Growing Care Gap? The Supply of Unpaid Care for Older People by their Adult Children in England to 2032. *Ageing and Society*, 35(01), 96-123.
- Prince, M., Knapp, M., Guerchet, M., McCrone, P., Prina, M., Comas-Herrera, A., Wittenberg, R., Adelaja, B., Hu, B., King, D. & Rehill, A. (2014) *Dementia UK Update*. London: Alzheimer's Society.

Overview

The 'GTC Conversations on Care' provide an opportunity to assess broad developments within the fields of health and social care and open new lines of enquiry through bringing together academics, practitioners, providers and policy advisors with backgrounds in health, business and management and the social sciences. The 'conversations' take the form of a presentation from a leading academic in the field of health and social care, particularly in relation to older people, followed by a Question and Answer session with the audience. Six 'conversations' were held in the academic year 2015-16, which were intended to address the pressing concerns outlined above:

- *Adult Social Care in England: Policy, Spending and Outcomes 2010 – 2015*, Dr Tania Burchardt, Director, CASE (Centre for Analysis of Social Exclusion) and Associate Professor, Department of Social Policy, London School of Economics and Political Science.
- *Assets-based Approaches to Adult Social Care – Developing a New Public Service Offer*, Professor Jon Glasby, Professor of Health and Social Care and Director of the Health Services Management Centre at the University of Birmingham.
- *The Law and the Right to Care in Old Age*, Professor Jonathan Herring, DM Wolfe-Clarendon Fellow and Lecturer in Law, Exeter College, University of Oxford.
- *Quality in Home Care: Searching for the Holy Grail*, Professor Jill Manthorpe, Professor of Social Work at King's College London, Director of the Social Care Workforce Research Unit and NIHR Senior Investigator Emeritus.
- *Policies to Support 'Informal' Carers: Do they do it Better Elsewhere?* Professor Sue Yeandle, Director of the Centre for International Research on Care Labour and Equalities (CIRCLE) at the University of Sheffield.
- *Inequality in Later Life: Class, Care and Caring*, Professor Christina Victor, Professor of Public Health and Vice-Dean (Research), in the School of Health Sciences and Social Care, Brunel University, London.

Adult Social Care in England: Policy, Spending and Outcomes 2010 – 2015, Dr Tania Burchardt



The GTC CARE INITIATIVE
‘Conversations on Care’
Green Templeton College

**Adult Social Care in England:
Policy, Spending and Outcomes 2010 - 2015**

Speaker: Dr Tania Burchardt, The London School of Economics

The GTC CARE INITIATIVE
Developing a broader understanding of social care and health care

Next ‘Conversation on Care’ takes place on Monday 23 November 2015:
Assets-based approaches to Adult Social Care – Developing a new Public Service Offer
Professor Jon Glasby, The Health Services Management Centre

Dr Tania Burchardt is Director, CASE (Centre for Analysis of Social Exclusion) and Associate Professor, Department of Social Policy, London School of Economics and Political Science.

Date of Presentation: 28th October 2015

Summary

Dr Burchardt reviewed the policy, spending and outcomes of the UK Coalition government, in power between 2010 and 2015, and outlined the implications for adult social care in England. She explained that the Coalition had inherited a system already under pressure due to: increasing life expectancy; increasing numbers of physically and cognitively impaired young people surviving into adulthood; multiple boundaries in financing and provision of social care; and emerging concerns over care quality. She provided an overview of spending: showing total local government funding in England to have fallen by 40 per cent between 2009/10 and 2014/15 and total local government spending on adult social care by 10.3 per cent in real terms. Spending on older people fell faster: by 2013/14, spending on people aged 65 plus had fallen by 17 per cent despite a 10 per cent increase in the number of people aged 65 or over, and a 9 per cent increase in the number of people aged 85 or over. Dr Burchardt outlined the challenges current governments face: the effective integration of health and social care; tackling high prevalence of poor standards of care and abuse; greater emphasis on prevention; creating “conditions that enable ‘relationships of care’ to flourish”; investing in the social care workforce; addressing unmet need and relieving pressure on unpaid carers; and reconciling further cuts with continued demographic pressure.

Key Insights and Points of Discussion

Dr Burchardt's presentation clearly demonstrated the consequences of the spending cuts which the Coalition government imposed upon local authorities, especially if these are located within wider concerns about the funding of care for older people. The 'intensification' or targeting of local authority services to a smaller number of older people with the greatest need means that a growing number of older people have unmet needs. There is a lack of knowledge about the consequences of these unmet needs, and in particular whether they continue to be unmet, and the lived experiences of the older people affected. Alternatively, if those needs are met (or partially met) in other ways, much needs to be understood about how, by whom, and the burden/costs placed upon those informal providers. Recent USA research has suggested that there are links between unmet needs in older people and their moving from living in the community into residential care provision. Research is urgently required in this area.

Some Relevant Reading

Age UK (2015) *Later Life in the United Kingdom October 2015 Factsheet*, September 2015 update: http://www.ageuk.org.uk/Documents/EN-GB/Factsheets/Later_Life_UK_factsheet.pdf?dtrk=true

Allen, S. M., Piette, E. R & Mor, V. (2014). The Adverse Consequences of Unmet Need among Older Persons Living in the Community: Dual-eligible versus Medicare-only beneficiaries. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 69(Suppl 1), S51-S58.

Burchardt, T., Evans, M. & Holder, H. (2015). Public Policy and Inequalities of Choice and Autonomy. *Social Policy and Administration*, 49(1), 44-67.

Fernández, J. L., Forder, J., Trukeschitz, B., Rokosová, M., & McDaid, D. (2009). *How Can European States Design Efficient, Equitable and Sustainable Funding Systems for Long-Term Care for Older People?*. Copenhagen: Regional Office for Europe and European Observatory on Health Systems and Policies, World Health Organization.

Vlachantoni, A., Shaw, R. J., Evandrou, M. & Falkingham, J. (2015). The Determinants of Receiving Social Care in Later Life in England. *Ageing and Society*, 35(02), 321-345.

Assets-based Approaches to Adult Social Care – Developing a New Public Service Offer,
Professor Jon Glasby



Jon Glasby is Professor of Health and Social Care and Director of the Health Services Management Centre at the University of Birmingham.

Date of Presentation: 23rd November 2015

Summary

Professor Glasby outlined the current challenges facing the provision of adult social care: demographic, social and technological changes; changing public expectations; and a difficult financial context. He suggested that current responses (partnership working; prevention and personalisation) are not working. New concepts and especially ‘asset based’ initiatives may offer an alternative. These include: social capital (bonding and bridging); assets-based community development (ABCD); ‘public value’; the independent living movement and a social model of disability (influenced by other civil rights movements); and a reconceptualisation of personalisation (drawing on social justice, citizenship and the inclusion movement). Professor Glasby suggested that these might inform a new approach to adult social care, one which is based on building on social capital and community resources, involving a return to community development linked to economic development. Professor Glasby asked what was delaying further development of such projects and suggested a number of questions needing to be asked: Will it actually work? How do we implement the cuts without cutting the ‘wrong’ things? Do we have the skills and experience anymore? Do we know how to ‘scale out’ rather than scale up? What will staff and local people make of it?

Key Insights and Points of Discussion

Professor Glasby's presentation highlighted both the current challenges facing adult social care – growing demand and diminishing resources – and the potential offered by an asset-based approach. He raised a number of interesting questions about why the approach has not been developed more in terms of current local projects. There was some discussion about this in the Questions and Answers section of the event. Key areas which were raised included: whether informal networks of support are available and can be mobilised; whether, even if they can be accessed, informal networks can match the quality and reliability of formal care provision; the cost implications of resourcing and supporting community based networks; the gender implications of increasing reliance upon informal networks; to what extent the asset-based approach is oriented towards younger, relatively higher functioning older people, rather than 'older' older people with significant physical and/or cognitive disabilities, particularly those with dementia. An overarching concern was whether an asset-based approach might mask the retreat of the state from the social care and support of older people.

Some Relevant Reading

- Brooks, F., & Kendall, S. (2013). Making Sense of Assets: What can an assets based approach offer public health?. *Critical Public Health*, 23(2), 127-130.
- Foot, J., & Hopkins, T. (2010). *A Glass Half-full: How an asset approach can improve community health and well-being*. London: Great Britain Improvement and Development Agency.
- Friedli, L. (2013) 'What We've Tried, Hasn't Worked': The politics of assets based public health. *Critical Public Health*, 23(2), 131-145.
- Hopkins, T., & Rippon, S. (2015). *Head, Hands and Heart: Asset-based approaches in health care*. London: The Health Foundation.
- Knapp, M., Bauer, A., Perkins, M., & Snell, T. (2013). Building Community Capital in Social Care: Is there an economic case?. *Community Development Journal*, 48(2), 313-331.
- MacLeod, M. A., & Emejulu, A. (2014). Neoliberalism with a Community Face? A critical analysis of asset-based community development in Scotland. *Journal of Community Practice*, 22(4), 430-450.

The Law and the Right to Care in Old Age, Professor Jonathan Herring

The GTC CARE INITIATIVE
'Conversations on Care'
Green Templeton College

The Law and the Right to Care in Old Age
Speaker: Jonathan Herring

The GTC CARE INITIATIVE
Developing a broader understanding of social care and
health care

Next 'Conversation on Care': Monday 29 February 2016
Quality in Home care – Searching for the Holy Grail
Professor Jill Manthorpe

Professor Jonathan Herring is DM Wolfe-Clarendon Fellow and Lecturer in Law, Exeter College, University of Oxford.

Date of Presentation: 10th February 2016

Summary

Professor Herring outlined his understanding of 'The Care Crisis' in relation to older people in the UK, before moving on to consider human rights in English Law, and to describe some key cases relating to older people in which human rights legislation has been applied. Professor Herring then considered the possibilities and limitations of human rights. In terms of limitations, a human rights based approach can: result in 'private' harms being overlooked; be problematic to prove and enforce; lead to a 'tick box' approach involving procedural and formalised responses that can work against personalised care and responsiveness and can set minimal rather than ideal standards; and sits uncomfortably with the rationing of care provision. On the other hand, human rights can offer a legal framework; can act as a 'bulwark against ageism, infantilisation and dehumanisation'; and embedding human rights into the way home care is provided can inform the delivery of high quality care, without necessarily increasing costs. Professor Herring concluded that human rights are not the sole answer, but have an important role to play in relation to older people and care. Ultimately, he argued that human rights are dependent on how they are applied, working best as an attitude or orientation, rather than a remedy.

Key Insights and Points of Discussion

Professor Herring's presentation highlighted both the strengths and weaknesses of a rights-based approach to care. The strengths cohere around an articulation of key entitlements, enshrined in law. The weaknesses lie in the generic nature of those entitlements, the thresholds for them (e.g. 'torture' has a very high threshold which is not normally satisfied by even the poorest quality of care) and the difficulties mobilising and enforcing rights in 'private' care contexts. As Professor Herring argued human rights are often most useful when applied in encouraging particular attitudes among care providers. They can also be extremely helpful when utilised by advocates speaking on behalf of older people in particular circumstances. However, such advocacy is contingent on there being advocates available to represent older people, and, particularly with current funding constraints, these are few and far between. Moreover human rights do not tackle the issue of the right to care as a resource, nor the rationing of care resources, especially during times of 'austerity'. It may be that care standards rather than a rights based approach may be more useful in addressing care quality. The 'right to care' remains an unresolved issue and enduring concern particularly given the growing body of research suggesting mounting unmet care needs among older people.

Some Relevant Reading

- British Institute of Human Rights (BIHR) (2010). *Your Human Rights: A Guide for Older People 2nd edition*. London: BIHR.
- Equality and Human Rights Commission (EHRC) (2011) *Close to Home: An inquiry into older people and human rights in home care*. London: EHRC.
- Fernandez, J. L., Snell, T. & Wistow, G. (2013). *Changes in the Patterns of Social Care Provision in England: 2005/6 to 2012/13*. Personal Social Services Research Unit PSSRU Discussion Paper 2867. Canterbury and London: University of Kent and London School of Economics.
- Ismail, S. Thorlby, R. & Holder, H. (2014) *Focus On: Social Care for Older People. Reductions in adult social services for older people in England*. Nuffield Quality Watch. London: The Health Foundation and Nuffield Trust
- Vlachantoni, A., Shaw, R. J., Evandrou, M. & Falkingham, J. (2015). The Determinants of Receiving Social Care in Later Life in England. *Ageing and Society*, 35(02), 321-345.

Quality in Home Care: Searching for the Holy Grail, Professor Jill Manthorpe



Jill Manthorpe is Professor of Social Work at King's College London, Director of the Social Care Workforce Research Unit and NIHR Senior Investigator Emeritus.

Date of Presentation: 29th February 2016

Summary

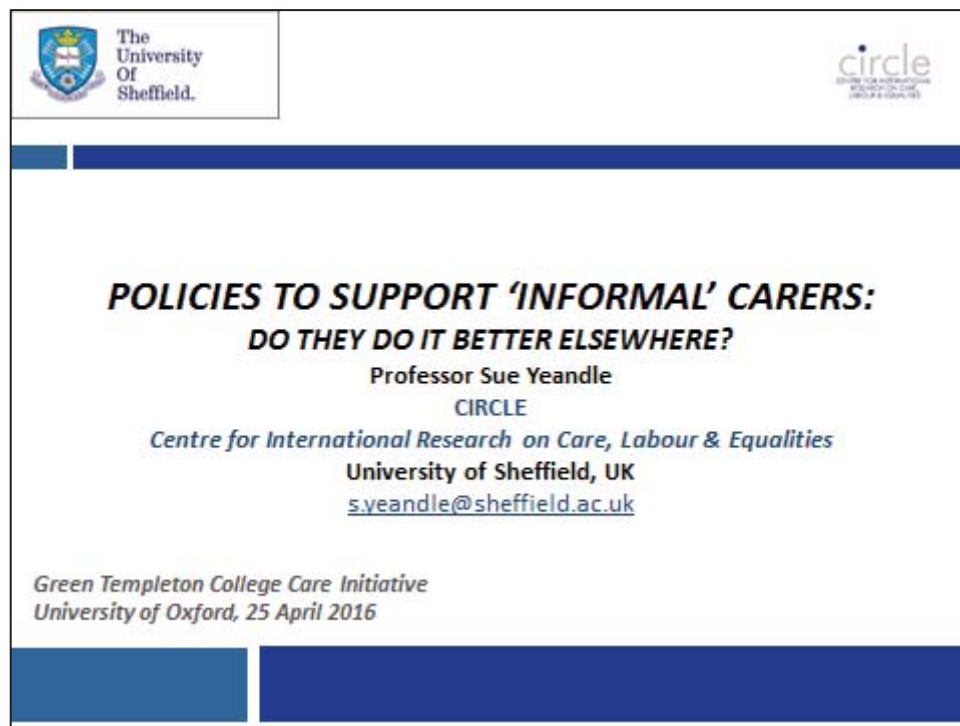
Professor Manthorpe outlined the historical backcloth of current debates about home care. She commented on the resilience of themes such as 'scientific managerialism', pay and conditions and employer/employee dynamics. She pointed to the powerful influence of the 'home help' service as a 'golden age' and to the divergent paths of home nursing and home care in the UK. Professor Manthorpe identified some of the tensions currently associated with home care in the UK: visits too brief; a lack of continuity of care; inexperienced carers; and rigid care plans. These problems are occurring against a background of reduced spending on social care. She also highlighted a number of challenges facing those who wish to address quality in home care, including: how such quality is (to be) assessed; how to describe and evaluate the home care contribution, including its economic contribution; and determining what outcomes to measure. Professor Manthorpe likened the longstanding concern about improving home care as the search for the Holy Grail. She located this in the wider context of similar concerns about care homes and hospitals, against a background of care still moving from being conceptualised as a private issue to one of public concern.

Key Insights and Points of Discussion

Professor Manthorpe's presentation, located in historical contexts, serves as a reminder of the enduring tensions about the provision of care to older people in their homes. As she argued, this is in many ways not a 'new' problem. However, it is exacerbated in the present day by an ageing demographic, changing family forms, increasing geographical mobility and dispersed extended families, which, together with the increased paid employment of women, have resulted in the decline in the availability of informal care. This, in turn, has led to increased demand for the provision of formal home care (most commonly provided by women), which tends to be poorly paid and culturally undervalued. The quality of such care is difficult to monitor because it takes place in the relative privacy of the home, and because the older people receiving that care are often vulnerable, isolated, and very reliant upon their care providers. Many home care providers are highly dedicated to the people they care for, and many are in vulnerable positions themselves, due to low pay and insecure employment contracts. The concerns about the quality of care must, then, be located in the wider context of the place of care in society, and the cultural worth placed on care itself, and those who provide it.

Some Relevant Reading

- Carr, S. (2014). *Pay, Conditions and Care Quality in Residential, Nursing and Domiciliary Services*. York: Joseph Rowntree Foundation.
- Chester, H., Hughes, J. & Challis, D. (2014). Commissioning Social Care for Older People: influencing the quality of direct care. *Ageing and Society*, 34(06), 930-950.
- Equality and Human Rights Commission (EHRC) (2011) *Close to Home: An inquiry into older people and human rights in home care*. London: EHRC.
- Lewis, J. & West, A. (2014). Re-Shaping Social Care Services for Older People in England: policy development and the problem of achieving 'good care'. *Journal of social policy*, 43(01), 1-18.
- Rodrigues, R. & Glendinning, C. (2015). Choice, Competition and Care - Developments in English Social Care and the Impacts on Providers and Older Users of Home Care Services. *Social Policy and Administration*, 49(5), 649-664.
- Willis, R., Khambhaita, P., Pathak, P. & Evandrou, M. (2015). Satisfaction with Social Care Services among South Asian and White British Older People: The need to understand the system. *Ageing and Society*, 36(5), 1364-1387.



Professor Sue Yeandle is Director of the Centre for International Research on Care Labour and Equalities (CIRCLE) at the University of Sheffield (and previously in the University of Leeds).

Date of Presentation: 25th April 2016

Summary

Professor Yeandle first explored the understanding, approach to and contribution of carers in the UK, where 12% of the population provide unpaid care. In 2015 this contribution was valued at £132 billion p.a. which equals the total cost of NHS spending and is over four times the annual UK Local Authority expenditure on social care services. The Care Act 2014 and the Children and Families Act 2014 strengthened the rights and recognition of carers in the social care system, bringing wider definition, the legal right to receive support, and personal budget statements Professor Yeandle then went on to compare the social policy and support provided for 'informal carers' in the UK, Australia, Canada, Sweden and Finland, and Japan. To do so she developed and applied an analytical framework comprising four elements: Financial Support (measures to prevent financial hardship for carers); Work-Care Reconciliation (workplace and life course flexibility for employees, employers, labour force); Services for Users and Carers (reliable, flexible, affordable, accessible and technology-enabled); Carer Recognition and Rights (economic, social moral case - value, respect, inclusion). Despite variation in how policy and provision are organised, Professor Yeandle identified the following common rationales across countries: demographic change and pressure; gender equality; sustainability; employer interests; managing care costs; and '21st century care' (care outside hospital; care outside institutions; independent living; the 'bedrock' of carers' support). She highlighted the opportunities for

international learning, mentoring, networking and sharing of ideas; and the potential for these to empower, inspire, promote the sharing of ideas, and raise the profile of ‘informal’ carers.

Key Insights and Points of Discussion

Professor Yeandle’s presentation and the subsequent discussion highlighted the vital contribution informal carers make across a range of different societies. This is the case in regard to both the inherent value of the care and support they provide, particularly for older people, and the economic savings they also provide to the state. Adequate care and support for informal carers themselves is essential in order to enable them to carry on caring. While there is increasing policy rhetoric in relation to supporting informal carers in the UK, and new legislation which enshrines their own rights to care and support, this has so far had variable impact on the lived experiences of informal carers, particularly those caring for, and supporting, older people. Professor Yeandle’s presentation demonstrated that these issues, while nationally framed and located, are international ones. In an increasingly globalised context, many of the issues and concerns affecting informal carers go beyond national boundaries and countries need to learn from each other’s policies and experience. Mobilising international networks offers many new opportunities not only to share knowledge and information but also to empower informal carers and to increase the possibilities to advocate with them and/or on their behalf. This in turn has the potential to create greater visibility and voice about the needs of informal carers and the centrality of supporting them for the states and societies which rely so heavily upon them.

Some Relevant Reading

Campbell, J. et al. (2010) Lessons from Public Long-Term Care Insurance in Germany and Japan. *Health Affairs*, 29(01), 87-95.

Cass, B. et al. (2014) The Challenge of Caring, Now and in the Future: Learning from across the world. University of Leeds, <http://circle.leeds.ac.uk/files/2014/05/Challenge-of-Caring-v6-low-res-WEB.pdf>

Jegermalm, M. & Sundström, G. (2013) Carers in Sweden: The public support they receive and the support they desire. *Journal of Care Services Management*, 7(1), 17-25.

Kröger, T. & Yeandle, S. (eds.) (2013) *Combining Paid Work and Family Care: Policies & experiences in international perspective*,. Bristol: Policy Press

McCaffrey, N, Gill, L et al. (2015) Important Features of Home-Based Support Services for Older Australians and their Informal Carers. *Health and Social Care in the Community*, 23(6), 654–664.

Williams, A.M. Wang, L. & Kitchen, P. (2016) Impacts of Care-Giving and Sources of Support: A comparison of end-of-life and non-end-of-life caregivers in Canada. *Health and Social Care in the Community*, 24(2), 214–224.



Christina Victor is Professor of Public Health and Vice-Dean (Research), in the School of Health Sciences and Social Care, Brunel University, London. She is also the editor of *Ageing and Society*.

Date of Presentation: 6th June 2016

Summary

Professor Victor's presentation addressed a number of areas: the focus of gerontology; inequalities in ageing along the lines of gender, class and ethnicity; inequalities in health in later life; and the need for, and provision of, social care. She provided an overview of the demographics of population ageing both worldwide and in the UK, considering how life expectancy in Europe and the UK varies according to class, gender, and ethnicity. Life expectancy at birth in 1900 was approximately 48 years, whereas it is now (in the developed world) approximately 80 years. Professor Victor then went on to discuss her research on life expectancy, health and care needs of older people in minority ethnic communities in the UK. The minority ethnic population aged 65+ in the UK comprise: Bangladeshi (4 per cent); Pakistani (5 per cent); Chinese (4 per cent); Indian (7 per cent); African Caribbean (13 per cent). White British women and men have a greater life expectancy (81 for women; 76 for men) than British women and men from Indian (79 for women; 76 for men), Pakistani (77 for women; 73 for men), Bangladeshi (77 for women; 73 for men), Black Caribbean (79 for women; 74 for men) and White Irish backgrounds (80 for women; 75 for men). They also have a higher disability-free life expectancy. Professor Victor emphasised the importance of engaging with community leaders to ensure active participation in research by older people from minority communities.

Key Insights and Points of Discussion

Professor Victor's presentation and the subsequent discussion highlighted the significance of diversity for health inequalities among older people in the UK. While she focused in her talk on class, gender and ethnicity, she also acknowledged other research in relation to health inequalities also experienced by older lesbian, gay, bisexual and trans* (LGBT*)¹ people in the UK (Westwood, 2016; Westwood and Price, 2016). These various inequalities often overlap and/or intersect: for example lower incomes experienced by migrants arriving in the UK in the 1950s and 1960s affect their (classed) poorer relative health outcomes in older age. Additionally, 'minority stress' is recognised as shaping health levels and experiences in later life, particularly the detrimental cumulative effects of social exclusion and low income on both physical and mental well-being. While there is a growing body of knowledge on the patterns of these later life inequalities, little is known as yet about how to prevent and/or mitigate them. There is an urgent need for further research in this area.

¹Trans* is an umbrella term which covers the gender identity spectrum: including (but not limited to) transgender, transsexual, transvestite, genderqueer, genderfluid, non-binary, genderless, agender, non-gendered, third gender, two-spirit and bigender.

Some Relevant Reading

- Corna, L. M. (2013). A Life Course Perspective on Socioeconomic Inequalities in Health: A critical review of conceptual frameworks. *Advances in Life Course Research*, 18(2), 150-159.
- Deaton, A. (2013). *The Great Escape: health, wealth, and the origins of inequality*. New York: Princeton University Press.
- Evandrou, M., Falkingham, J., Feng, Z. & Vlachantoni, A. (2016). Ethnic Inequalities in Limiting Health and Self-Reported Health in Later Life Revisited. *Journal of Epidemiology and Community Health*, 70(7), 653-662.
- Tinker, A. (2014). *Older People in Modern Society*. London: Routledge.
- Victor, C. R., Martin, W., & Zubair, M. (2012). Families and Caring amongst Older People in South Asian Communities in the UK: A pilot study. *European Journal of Social Work*, 15(1), 81-96.
- Westwood, S. (2016). LGBT Ageing in the UK: Spatial inequalities in older age housing/care provision. *Journal of Poverty and Social Justice*. <http://dx.doi.org/10.1332/175982716X14538098308249>
- Westwood, S. & Price, E. (Eds) (2016) *Lesbian, Gay, Bisexual and Trans* (LGBT*) Individuals Living with Dementia: Concepts, practice, rights*. Abingdon: Routledge.

Common Discussion Points

The six presentations raised a number of common themes and discussion points as well as highlighting a critical research and policy agenda.

Rationing, rights and resources

An overarching theme transecting the majority of the presentations was the tension between older people's needs for care and support and the availability of such care and support, both informal and formal. Sue Yeandle highlighted the ongoing concerns about a lack of recognition and support for the vital contribution made by informal carers. Other speakers addressed the problems of the tightening of rationing of formal care and support provision, in the context of increasing demand and diminishing resources and/or resource allocation. As Jonathan Herring demonstrated in his presentation, there is no fundamental 'right to care' in the UK, and human rights legislation only has a limited amount to offer in this regard. This leaves outstanding the issue of whether there should be a 'right to care' enshrined in law, and whether that care should be wider reaching than the Care Act's 'substantial' and 'critical' thresholds for entitlement to basic care and support. There is a danger that conversations about what resources are available particularly during times of 'austerity' may occlude and obscure wider arguments about what *should* be available (Friedli, 2013; MacLeod & Emejulu, 2014).

Unmet needs

Each of the presentations highlighted the issue of unmet need, specifically in relation to: informal carers (Sue Yeandle); health inequalities experienced by older people from Black and minority ethnic (BME) communities (Christina Victor); quality of home care (Jill Manthorpe); care quality more broadly (Jonathan Herring); and the availability of formal care provision. Tania Burchardt demonstrated the consequences of recent cuts in funding for older people in need of care and support. Only those with the greatest need are now being funded for formal services, leaving growing numbers of older people experiencing unmet needs. We do not know whether/how those needs are being met outside of the formal system and the implications of developments for older people themselves and their informal care providers (if they are increasing their support to meet the unmet needs for example). Older people who live alone, particularly those with limited informal social support networks, are likely to be in a position of heightened vulnerability (Cramm et al, 2013). It is not unreasonable to wonder whether they are at increased risk of entering residential care provision as a result. Again, this is an area which warrants urgent research.

Re-locating responsibility for care and support

Jon Glasby's presentation on an asset-based approach highlights an area of growing discourse in the areas of social policy and community development (McLean and McNeice, 2012; Hopkins and Rippon, 2015). In response to the growing shortage of informal carers and diminishing formal resources, there is the hope that local communities can be mobilised to become alternative sources of support for older people. However, some researchers have begun to question whether community volunteers can be relied upon as viable substitutes for formal providers of care and support (Mountain et al, 2015). Moreover focusing on supporting 'younger older' people in the third age can serve to obscure and detract attention from the unavoidable

high support needs of many of those ‘older older’ people, in the fourth age (Gilleard and Higgs, 2010), a high proportion of whom will be living with the symptoms of dementia (Knapp et al, 2007).

The politics of care

Each of the presentations also highlighted that care is a political issue, deeply embedded in social and cultural contexts (Daly, 2002). The meaning(s) of care (Barnes, 2012), the cultural devaluation of care, particularly personal care (Twigg, 2000), and the ethics of care (Held, 2006), have been the focus of long-standing academic debate. This debate is now playing itself out tangibly in terms of the lived experience of older people, specifically in relation to who should be providing older people with care and support, when, how and in what way, and in terms of what support should be provided to carers (both formal and informal). The privatisation of gendered care has long been critiqued for the inequalities and disadvantages it creates for ‘informal carers’, who are most likely to be women (Haber Kern, Schmid & Szydlik, 2015). Such inequalities and disadvantages include those relating to material (income, pension accrual, building capital), health (physical and mental well-being), social (access to social relationships and support), affective (love, care and solidarity) and political (civic engagement and participation) resources. A number of key authors have argued that ‘informal carers’ are not only entitled to compensation for the informal care they provide, but that they are actually entitled to *care* in their own right.

Eva Feder Kittay (1999, 2001) has advanced the notion of *doulia* i.e. the principle that those who provide care are less able to care for themselves and therefore are entitled to care from others and especially the state. This goes beyond present notions of supporting carers to continue providing caring for others, emphasising the carer’s own need for care. Only if carers have their needs met through *doulia* (care for the carer) can they have equal access to: affective support, autonomy, choice and control; citizenship; and ‘parity of participation’ (Fraser, 2007, page 27) in society. West (2002) developed Kittay’s argument further to suggest that there should be a ‘right to care’ for informal carers. West suggests that this should be provided to an informal carer ‘so as to assure that she can provide adequate care without endangering herself and her dependants’ (page 111). This concept of endangerment is quite a high threshold, however, and fails to reach care ethicists’ greater ambitions to see carers’ own needs met in order for them to flourish and lead fully engaged and participative lives as equal citizens (Bubeck, 2002). The place of carers’ rights to their own care is as yet unresolved in policy and practice (Deacon, 2007), particularly in present times of austerity. There would however appear to be a gap between care ethicists’ assertions about carers’ rights to their own care, social policy commitment to carer support, and the care and support informal carers actually receive. This argument can also be extended in relation to low-paid formal carers (also commonly women) in both home care and residential care contexts, returning us again to the extent to which care is (de-)valued in society.

Diversity, older people and care

Christina Victor’s presentation reminded us that older people are not a homogenous group, and that indeed there is great diversity within and among older people (Tinker, 2014). Older people and their experiences of later life vary and are affected by a wide range of social positions, including: age; class and socioeconomic position; disability; gender, sexuality/sexual identity; trans* identities; race, ethnicity and culture; and religion. Their experiences of ageing are also

shaped by geographical location (particularly in terms of whether they live in rural or urban spaces) and by relationship status (married/partnered; living together or living-apart-together; parents/grandparents or child/grandchild-free; with/without extended social networks and/or intergenerational support). Each of these factors does not operate in isolation, but instead intersect to produce complex and uneven outcomes in later life. While Christina Victor highlighted the health inequalities experienced by older people from minority ethnic backgrounds, there are wide ranging inequalities beyond issues of health. These include, not least of all, access to informal care and social support, and to formal services which are culturally sensitive and geared up to meet the needs of majority and minority populations. During times of austerity, the risk is that issues of diversity may be perceived as luxuries which can become sidelined (King, 2015). While the personalisation agenda (Department of Health, 2007) is intended to enable people, including older people, with culturally appropriate services (Netten et al, 2011), this is contingent on their ability to mobilise such services (Rummery, 2011) and becomes redundant if such services are not available. This, then, is a crucial site of inequality for older people in relation to health and social care in later life.

Conclusion

The ‘GTC Conversations on Care’ seminar series 2015-16 provided a forum for six informative and thought-provoking presentations delivered by experts in the field of older people and social care. These have highlighted the pressing issues, current debates, and tensions in the field, particularly in the context of an ageing demographic, increasing demand for social care and support and associated challenges during times of resource constraints. These conversations have, in turn, informed the identification of a critical research agenda in relation to older people and social care, as follows:

- There is a need to explore the lived experience of informal and formal carers of older people, both in terms of the implications for the older person themselves and for the carers’ own wellbeing and need for care and support.
- There is a need to explore further the issue of a ‘right to care’ outside of the current debate about diminishing and increasingly rationed formal care and support provision, in order to keep sight of the care to which older people should be entitled, compared with what is actually available.
- The consequences of unmet need for older people and their informal networks of support require urgent research, both in terms of the lived experiences of older people and the (gendered) implications for their informal support networks.
- The increasingly vaunted asset-based approach requires both theoretical and empirical interrogation. Questions need to be posed about whether the needed community resources exist, particularly if they are to be increasingly relied upon in the face the growing withdrawal of the state from the provision of care and support for older people.
- The heterogeneity of older people needs to be considered in all of this research, together with associated inequalities of access and outcomes in relation to appropriate care and support.

The ‘GTC Conversations on Care’ seminar series also highlighted a number of social policy implications which merit consideration and further investigation:

- There is a tension between the prevention agenda in the Care Act 2014 and the growing constraints under Care Act guidelines to provide services to only those older people who have ‘substantial and critical’ needs, i.e. when the time for preventative services has already passed.
- The growth of an asset-based agenda in social and community policy agendas, but without empirical support, might best be understood as a political strategy rather than a proven solution to the tensions between care needs and diminishing resources
- The increasing emphasis on community based informal networks of support has not been thought through in terms of the implications for informal carers, and their own needs for support.
- The increasing emphasis on informal community based support needs to be thought through in terms of the implications for adult safeguarding issues.
- The ongoing under-resourcing of adult social care is a problem which will not go away, and, with an ageing population, is one which is set to increase.
- If there is to be increasing reliance on community-based support, then consideration needs to be given to how communities can be (re-)structured to support informal care, i.e. with a re-balancing of work/care time, greater support for employees with (adult) care responsibilities, and greater rewards for those who provide care, both paid and unpaid.

These conversations will be taken forward and developed further in the 2016-2017 ‘GTC Conversations on Care’ seminar series, which it is anticipated will be equally productive.

References

- Barnes, M. (2012). *Care in Everyday Life: An ethic of care in practice*. Bristol: Policy Press.
- Bubeck, D. (2002) Justice and the Labor of Care. In: E.F. Kittay & E.K. Feder (Eds) *The Subject of Care: Feminist perspectives on dependency*, pp. 160-185. Oxford: Rowman & Littlefield.
- Cramm, J. M., Van Dijk, H. M. & Nieboer, A. P. (2013). The Importance of Neighborhood Social Cohesion and Social Capital for the Well Being of Older Adults in the Community. *The Gerontologist*, 53(1), 142-152.
- Daly, M. (2002). Care as a Good for Social policy. *Journal of Social Policy*, 31(2), 251-270.
- Daly, M. & Westwood, S. (submitted) An Asset-Based Approach, Older People and Social Care: An analysis and critique. Submitted to *Ageing and Society*.
- Deacon, A. (2007). Civic Labour or Doulia? Care, reciprocity and welfare. *Social Policy and Society*, 6(04), 481-490.
- Department of Health (2007). *Putting People First: A shared vision and commitment to the transformation of adult social care*. London: The Stationery Office.
- Fraser, N. (2007). Feminist Politics in the Age of Recognition: A two-dimension approach to gender justice. *Studies in Social Justice*, 1(1), 23-35.
- Friedli, L. (2013). ‘What We’ve Tried, Hasn’t Worked’: The politics of assets based public health. *Critical Public Health*, 23(2), 131-45.

- Haberkern, K., Schmid, T. & Szydlik, M. (2015). Gender Differences in Intergenerational Care in European Welfare States. *Ageing and Society*, 35(02), 298-320.
- Held, V. (2006). *The Ethics of Care: Personal, Political, Global*. Oxford: Oxford University Press.
- Hopkins, T. & Rippon, S. (2015). *Head, Hands and Heart: Asset-based Approaches in Health Care*. London: The Health Foundation.
- Gilleard, C. & Higgs, P. (2010). Aging Without Agency: Theorizing the fourth age. *Ageing & Mental Health*, 14(2), 121-128.
- King, A. (2015). Prepare for Impact? Reflecting on Knowledge Exchange Work to Improve Services for Older LGBT People in Times of Austerity. *Social Policy and Society*, 14(01), 15-27.
- Kittay, E. F. (1999). *Love's Labor: Essays on Women, Equality and Dependency*. New York: Routledge.
- Kittay, E. F. (2001). A Feminist Public Ethic of Care Meets the New Communitarian Family Policy. *Ethics*, 111 (April), 523–547
- Knapp, M., Prince, M., Albanese, E., Banerjee, S., Dhanasiri, S., Fernandez, J., Ferri, C., McCrone, P., Snell, T. & Stewart, R. (2007). *Dementia UK*. A report to the Alzheimer's Society on the prevalence and economic cost of dementia in the UK produced by King's College London and London School of Economics. Alzheimer's Society: London.
- MacLeod, M. A. & Emejulu, A. (2014). Neoliberalism with a Community Face? A critical analysis of asset-based community development in Scotland. *Journal of Community Practice*, (22) 4, 430-50.
- McLean, J. & McNeice, V. (2012). *Assets in Action: Illustrating Asset Based Approaches for Health Improvement*. Glasgow: Glasgow Centre for Population Health.
- Mountain, G., Gossage-Worrall, R., Cattan, M., & Bowling, A. (2015). Only Available to a Selected Few? Is it Feasible to Rely on a Volunteer Workforce for Complex Intervention Delivery? *Health & Social Care in the Community*. DOI: 10.1111/hsc.12285
- Netten, A., Jones, K., Knapp, M., Fernandez, J.L., Challis, D., Glendinning, C., Jacobs, S., Manthorpe, J., Moran, N., Stevens, M. & Wilberforce, M. (2011). Personalisation through Individual Budgets: Does it Work and for Whom? *British Journal of Social Work*, 42(8), 1556-1573.
- Rummery, K. (2011) A Comparative Analysis of Personalisation: Balancing an Ethic of Care with User Empowerment, *Ethics and Social Welfare*, 5(2), 138-152.
- Tinker, A. (2014). *Older People in Modern Society*. Routledge.
- Twigg, J. (2000). Carework as a Form of Bodywork. *Ageing and Society*, 20, 389-411.
- West R. (2002) The Right to Care. In: E.F. Kittay & E.K. Feder (Eds) *The Subject of Care: Feminist Perspectives on Dependency*, pp. 88–114. Oxford: Rowman & Littlefield.

4. OTHER ACTIVITIES ASSOCIATED WITH THE INITIATIVE

In conjunction with the Department of Social Policy and Intervention, University of Oxford, a state of the art interdisciplinary review of the literature on social care for older people in the UK was undertaken, paying particular attention to home-based and community care. The purpose of the review was to identify key evidence, synthesise that evidence and identify gaps in the evidence, with the aim of developing a cutting-edge research agenda. The report which presented the findings of the review, 'Social Care and Older People in Home and Community Contexts: A Review of Existing Research and Evidence', has been published as a Working Paper on the Department for Social Policy and Intervention's website.

5. THE YEAR AHEAD

2016-17 will involve a further series of 'GTC Conversations on Care'. Two presentations are scheduled for Michaelmas Term: the first by Professor Mary Daly and Dr Sue Westwood, outlining highlights from their interdisciplinary review of the literature on social care for older people in the UK; the second by Dr Athina Vlachantoni, Associate Professor in Gerontology, Centre for Research on Ageing, University of Southampton. Dr Vlachantoni will be addressing inequalities in access to social care among older people in the UK. In Hilary and Trinity terms, the aim is to invite speakers to present on the following topics: dementia 'citizenship' and social care; 'choice', social care and older people; the personalisation agenda in times of austerity; safeguarding, social care and older people.

Additionally, advance discussions are also underway, in conjunction with Age UK Oxfordshire and Citizens Advice Oxfordshire, for a half day seminar (November/December 2016) on the provision of housing with care for older people, with a particular focus on local authority and third sector partnerships.

CONTACTS AND STEERING GROUP

Professor Mary Daly (mary.daly@spi.ox.ac.uk), Department of Social Policy and Intervention, University of Oxford.

Dr Richard Cuthbertson, Senior Research Fellow, Saïd Business School, University of Oxford.

Richard McManus, Professor of Primary Care, Department of Primary Health Care Sciences, University of Oxford.

Dr Sian Rees, Director, Oxford Health Experiences Institute (HEXI), University of Oxford.

David Perry, Chairman RESEC Foundation (Research in Specialist and Elderly Care).

Sophie Kendall, Oxfordshire County Council.

Research Officer: Dr Sue Westwood, Department of Social Policy and Intervention, University of Oxford.

Academic Projects Manager: Ruth Loseby, Green Templeton College.

Academic Projects Administrator: Donna McMenemy, Green Templeton College.

Further Information from: Donna McMenemy, Green Templeton College:
donna.mcmenemy@gtc.ox.ac.uk

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Green Templeton College

43 Woodstock Road

Oxford

OX2 6HG

United Kingdom

Tel. +44 (0)1865 274770

Fax. +44 (0)1865 274796

Care Initiative Project Website: <http://www.gtc.ox.ac.uk/research-centres/care-initiative.html>