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# ILPN Conference 2016: Abstracts

## Plenary abstracts

### **Demographic and social change and long-term care demand**

***Professor Emily Grundy***

*London School of Economics and Political Science*

Population ageing, and in particular the growth of the oldest old, represents a challenge for the provision of long-term care. Moreover it is often assumed that, for both demographic and social reasons the supply of family carers, may be diminishing just as needs for such care increase. In this presentation I will review demographic drivers of the change in the numbers and proportions of older old people and demographic availability of close family (spouses and children). I will also review some of the evidence on possible changes in provision of family care and how this may interact with provision of formal care. I will also consider socio-economic differences in use of various forms of care.

### **Healthy ageing and long term care for older people: a global perspective**

***Professor Anne Margriet Pot***

*World Health Organization*

In the past year there has been increased political momentum for comprehensive action on population ageing and long-term care. In October 2015, the World Health Organization released the first ever World report on ageing and health. The World report compiles the best available scientific evidence and outlines a framework for action to foster Healthy Ageing built around the new concept of functional ability. It also provided the basis for a Global Strategy and Action Plan (GSAP) on ageing and health which was adopted in May 2016 by the World Health Assembly - comprising the Health Ministers or their delegates from the WHO's 194 Member States. One of the strategic objectives included in the GSAP, is the development of sustainable and equitable systems for providing long-term care, at home, and in communities and institutions. In the 21st century, no country can afford not to have a comprehensive system of Long-Term Care (LTC) as is stated in the GSAP. The goal of LTC-systems should be to maintain a level of functional ability in older people who have or are at high risk of significant losses of capacity, and ensure that this care is consistent with their basic rights, fundamental freedoms and human dignity. The challenges to build comprehensive LTC-systems in different resourced settings around the world, also in low and middle income countries, will be discussed in further detail.

### **The economics of integration: what do we know?**

***Professor R. Tamara Konetzka***

*University of Chicago*

The need for more coordination across health care settings is taken as self-evident. Fragmented payment systems and setting-specific incentives and information technology are often blamed for fragmented health care. Mounting evidence from the medical and health services literature suggests that fragmented care is unsafe for patients and expensive for the health care system. Accordingly, policies and interventions to increase coordination have become increasingly prevalent. In the United States, recent health care reform under the Affordable Care Act established Medicare Accountable Care Organizations (ACOs) where payers and providers take on responsibility for managing the health of their members across health care settings and are financially accountable for providing high-quality and low-cost care. Other examples of payment reforms that encourage coordination include bundled payments, which combine payments across provider settings for a single episode of care, and financial penalties for hospitals with higher-than-expected readmission rates, intended to encourage hospitals to monitor post-discharge care. These policies are likely

to create new incentives for providers to optimize care across health care settings, potentially through integration.

However, economists have long thought of integration as a double-edged sword: Theoretically, it can serve to achieve efficiencies by facilitating coordination of care and better allocation of resources across settings. On the other hand, it can be anti-competitive: Integrated providers refer patients to, and accept patients from, within the integrated system, thus limiting consumer choice and limiting access to referrals by providers outside the integrated system. With less competition, incentives for quality and efficiency may be blunted. Thus, while integration is expected in response to emerging policies encouraging coordination, the result may not be higher quality or lower costs.

In this presentation, the policy context of integration, the theoretical underpinnings, and the empirical evidence on the economics of integration in health care settings will be reviewed and summarized. The result is that the benefits of integration are far from self-evident. The achievement of the goals of increased coordination depends on the underlying payment policy, the strength of the incentives facing providers, and the countervailing anti-competitive effects of consolidation.

## **Attracting and retaining workforce in the long-term care sector**

### ***Dr Matthias von Schwanenflügel***

*Head of the Directorate-General 'Demographic Change, Senior Citizens, Non-statutory Welfare', Federal Ministry for Family Affairs, Senior Citizens, Women and Youth, Berlin*

The need for action to ensure the skilled labour force in geriatric care is indisputable. Surveys of the Federal Employment Agency revealed that in 2015, on average 100 job vacancies were met by only 31 skilled geriatric nurses registered as seeking employment. Due to the demographic developments (ageing populations) this situation will continue to aggravate. In 2030 there will be a shortage of 250.000 trained nurses in Germany.

We need a holistic approach to solve this challenge, to include:

1. Reform of LTC law to modernize the system and secure more money.
2. Helping families and relatives with a modernized care giving leave act.
3. Geriatric care training and qualification campaign to encourage people to pick up the training.
4. Reform of nursing professions to modernize the training and profession.

Germany has implemented and is still discussing the last step of an extensive reform of the LTC law which will add more than 5 billion Euros on top of the current system. The reform will affect the wages of professional care givers as well. A reform of the care-giving leave act was implemented in 2015 which supports families and relatives with their often difficult task of caring.

To ensure that the demand for qualified personnel in geriatric care is met, the Federal Government started the 'Geriatric care training and qualification campaign'. Positive trend in the number of trainees: the school year 2013/2014 marked a new peak with more than 26,700 new staff nationwide starting geriatric care training. At present the Deutscher Bundestag is discussing a bill to modernize the nursing training and profession. With the reform having been prepared for many years we seek to combine the training courses in geriatric care, nursing care and paediatric nursing care, which have been separately regulated to date, thus creating a new generalist nursing training in the Act on Nursing Professions. - Germany is merging all three professions to one. Closely linked to the reform is a general modernization of the nursing training and the introduction of a new, standardized nursing profession. We are creating the foundation for a new career pattern which will meet the changing needs. The reform of nursing professions addresses the background situation and the described changes by means of the following objectives:

- improve the quality of the training,
- increase the flexibility of deployment and the mobility of nursing personnel,
- boost the attractiveness of the training and the nursing profession,
- wage adjustment

## Individual presentations (by presenting author's name)

### **The care profiles during the last years of life – the impact of dementia and age in 1998 and 2013**

***Mari Aaltonen***

Country: Finland

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Marja Jylhä, School of Health Sciences and Gerontology Research Center, University of Tampere, Finland

*Thematic area:* Housing and care

*Objective:* With increasing longevity, death is postponed to very old age. Due very old age functional impairment and dementia are more prominent during the last years and months of life. This affects the need for care and care arrangements. The aim of this study is to investigate how the care profiles in last two years of life differ by dementia diagnosis and age in those who died in 1998 or in 2013.

*Data:* The study included all people who died at the age of 70 or older in the years 1998 or 2013 in Finland (N 72 203). Data were drawn from nationwide health and social care registers maintained by National Institute for Health and Welfare, and The Causes of Death Register, maintained by Statistics Finland. Data included each individual's hospital and long-term care use in last 730 days. Dementia diagnosis was identified from registers with ICD10 codes F00-03, G30.

*Methods:* Identification of profiles was based on days stayed in care and at home, and end-of-life care transitions. They were constructed with sequential profiling scheme. Profiles were compared between people with and without dementia, and between age groups 70-79, 80-89, and 90 or over.

*Results:* Between the years 1998 and 2013 the proportion of people with dementia increased from 22% to 34%. Simultaneously, the proportion of those who died at the age of 90 increased from 26% to 36% in those with dementia, and from 14% to 21% in those without dementia. The care profiles differed clearly between those with and without dementia, but the differences remained the same between the study years. Over a half of those with dementia but less than every fifth of those without dementia stayed the majority or the entire last two years in care. Of those with dementia one third, and of those without dementia three out of four, stayed at home until the last months of life. Staying at home without any inpatient care at the end of life was rare especially for those with dementia. Irrespective of dementia diagnosis, being in care at least one of the two years was most frequent among those aged 90 or older. Yet being in care at least for one year became less frequent, and both, people with and without dementia, spent more time at home in 2013 than in 1998; even the oldest age groups stayed more frequently the majority of the last two years at home in 2013 than in 1998.

*Policy implications:* Due to increasing longevity the frequency of dementia is growing. Age and dementia remained major drivers of the use of long-term care although the increasing number of the oldest and those with dementia were also living outside formal care facilities near the time of death. This is probably a result of the Finnish care policy that prefers staying at home as long as possible over institutional care. The

increasing longevity with increasing number of people in poor health is a great challenge for both home care and long-term care.

## **Cost-benefit analysis of functional adaptation at home for reducing assistance needs and preventing falls: the case of Barcelona**

***Estefania Alaminos***

Country: Spain

*Riskcenter-Universitat de Barcelona*

Co-authors: Ramon Alemany, Riskcenter-Universitat de Barcelona

Mercedes Ayuso, Riskcenter-Universitat de Barcelona

Montserrat Guillen, Riskcenter-Universitat de Barcelona

*Thematic area:* Housing and care

**Objective:** To provide an economic assessment of a public programme aimed at providing support products and perform works at home for a sample of people over 65 years living in the city of Barcelona in 2013. A cost-benefit analysis of the program has been carried out taking into account not only the expected reduction in care needs, but also the reduction in the expected number of falls/accidents at home.

**Data and methods:** We work with a sample of 454 people aged 65 or older who have limitations to perform daily tasks without support, 55% receive public long-term care benefits, 75% are women and 25% are men. The most frequent age group is 80 to 89 years. They are individuals who mostly live alone but receive care from third parties to perform basic daily activities. Two types of actions are considered: a) providing technical support products (82% of cases); b) performing works in the house (18% of cases). An indicator of self-perception of the need of care (IAPD) is created based on the subjective assessment on their limitations to perform basic activities of daily life. The scores are analysed before and after the intervention and the economic consequences are calculated.

**Results:** Men have a higher value of IAPD before and after interventions than women. In both cases, a reduction in the need for care is observed but a larger reduction is observed for women (the percentage of reduction is 33.5% for men and 35.81% for women). The reduction in the IAPD indicator is about 36.70% for those in the age group between 65 and 79 years, 38.46% for the group 80 to 84 years, 33.80% for the age group 85 to 89 years, and 31.55% for people aged 90 or more years. Works at home result in a higher reduction (45%) than the provision of technical support products (33%). In economic terms, for every euro invested in technical products, the annual savings range between 2.74 and 3.71 euros, taking into account lower requirements for third party support and prevention of different types of falls. The repayment of the investment is less than 5 months. In the case of works at home, the yield ranges from 5 to 6.35 euros, with a maximum repayment term of 1 year. Performance is positive in all scenarios analysed.

**Policy implications:** The cost-benefit analysis conducted confirms the efficiency of preventive policies. Governments should increase budget allocations aimed at this type of action taking into account the high yields and the expected effect on the quality of life and long-term care needs.

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# **The impact of workforce composition and characteristics on English care home quality**

**Stephen Allan**

Country: United Kingdom

University of Kent

*Thematic area:* Workforce and migrant workers

*Background and aim:* Social care is a highly labour-intensive industry and therefore issues around wage rates, turnover, and contracts are likely to impact on quality. Currently the UK care home sector has relatively high levels of staff turnover and vacancy rates (Skills for Care, 2015) and there is a potential future workforce shortage (ILC, 2015). US evidence (e.g. Bostick et al., 2006; Castle et al., 2008; Castle 2009) has generally found that poor workforce characteristics (e.g. higher turnover, lower levels of staffing) have a significant negative effect on quality indicators, but there is very little evidence for the UK.

The aim of this paper is to estimate the impact of workforce composition on the quality of English care homes. We hypothesise that better work conditions (e.g. higher pay, lower staff turnover, fewer temporary workers) will lead to higher quality ratings in care homes.

*Data and methods:* The analysis uses the national health and social care regulator (CQC) database of registered care homes and their CQC quality rating at 1st March 2016, matched with care homes data available from the market specialists Laing & Buisson, and the Skills for Care National Minimum Dataset for Social Care (NMDS-SC) from 2014/15. The NMDS-SC is a rich source of information on care provider staff characteristics and staffing levels in England. Data was available on over 7,500 independent sector (i.e. for profit/voluntary) care homes in the year from May 2014 to April 2015.

We estimate probit models of a binary measure of CQC quality rating and examine how this is impacted by local area workforce characteristics (average care worker wage, staff turnover rate, percent of temporary workers, all at postcode-district level). The regressions include controls for care home- (e.g. type of care home, size, sector) and local area-level (e.g. level of needs, older population) characteristics, and the level of competition that a care home faces.

Two assumptions are made: first, that the impact of staff pay and conditions will take time to impact on care home quality; and second that local social care market conditions will impact on individual care homes. Whilst the time-lagged and geographical nature of the workforce data should mitigate potential reverse causation issues (i.e. quality impacting on staffing decisions), we use spatial instrumental variables to control for the potential endogenous relationship between quality and both staff conditions and competition.

*Results and policy implications:* The findings suggest that local workforce characteristics do have a significant impact on quality. The results are based on a cross-section and only confirm a correlation between quality and workforce characteristics. Causation would have to be examined using a longitudinal analysis. This is an interesting finding for policy given that care providers are currently facing both income pressures as a result of the continued climate of public sector spending reductions and cost pressures due to the introduction of the new national living wage.

## **When frontline workers exercise their discretion: evidence from care-needs certification for long-term care insurance in Japan**

**Reiko Arami**

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*Thematic area:* Institutional dynamics and politics

*Objective:* Japan has become the most rapidly aging country in Asia. As the decentralization of welfare policies in Japan continues, frontline welfare workers play an increasingly important role in shaping the policy outcomes of the welfare state, including the realm of long-term care policy.

The purpose of this paper is to examine when and how Care-Needs Certification investigators for Japan's long-term care insurance (LTCI) programs exercise their discretion, with particular attention to how their decisions might be made by considering the local officials that manage them as well as their clients. As part of implementing this program, the government has delegated part of the process of determining eligibility to non-state actors.

The investigators' motivations and their behaviors are considered to be different from those of traditional street-level bureaucrats. In this sense, the investigators for Care-Needs Certification in Japan are 'new' frontline workers. So far few studies since Smith and Lipsky (1993) have explored how new frontline workers are disciplined by the local officials and clients of LTCI and when investigators exercise their discretion. There are also very few studies on the policy implementation process of long-term care insurance systems and welfare benefits that require considering the 'needs' of both the person who receives care and those who take care of the elderly. The existing literature generally considers the Care-Needs Certification system of Japan to be 'centralized' and no variations of Care-Needs Certification are supposed, leaving the possibility of variations unexamined.

*Data and methods:* I use data from an original survey that was distributed in the summer of 2012 to investigators in the Fukui Prefecture, which is a rural area of Japan. The survey response rate was 60.0% (N=562). I also interviewed in-depth twenty investigators who answered the survey. Using both qualitative and quantitative data, I explore when and how frontline workers exercise their discretion in view of organizational management.

*Results:* The results show that the level of mutual trust between LTCI investigators and the local officials who supervise them has a significant influence on exercising their discretion and the relationship between the investigators and the clients. Previous research suggests that supervisors work hard to eliminate worker discretion, but my analysis suggests that investigators, who are a new kind of frontline workers, come to their own conclusions based on their beliefs on how other actors, such as local officials and clients, tend to act.

*Policy implications:* The more that government tries to make adjustments to manage investigators more uniformly, the less successful the government is, and the less investigators are able to grasp clients' real needs.

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## **OPTIMISTIC: A care model for addressing hospitalization risk of long-stay nursing facility residents**

**Greg Arling**

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*Thematic area: Care models*

**Objective:** Many hospitalizations of nursing facility (NF) residents are thought to be avoidable. Unnecessary hospitalizations are burdensome for frail elders and wasteful of health care resources. Policymakers in the US have centered attention on public reporting and payment policies to prevent 30-day re-hospitalization of short-stay, post-acute NF residents with medical diagnoses, such as heart failure, COPD or pneumonia, that indicate preventability. Little attention has been given to hospitalization risk for long-stay NF residents who have unique needs and care requirements that go beyond a limited set of medical diagnoses and that could be addressed through better resource targeting and quality improvement strategies.

Our objectives are to identify risk factors for hospitalization of long-stay NF residents, and describe the application of findings within an innovative care model, the OPTIMISTIC project (Optimizing Patient Transfers, Impacting Medical Quality, and Improving Symptoms: Transforming Institutional Care).

OPTIMISTIC is part of a national demonstration funded by the US Centers for Medicare and Medicaid Services (CMS) to reduce avoidable hospital transfers among long-stay NF residents. The project's clinical staff of advanced practice nurses (APNs) and registered nurses (RNs) promotes proactive chronic care management, urgent care and robust transitional care services for residents in 19 partnering NFs in central Indiana. A multidisciplinary team of geriatricians and nurses supports clinical staff. Independent evaluators found a significant reduction in hospitalization rates in OPTIMISTIC facilities between 2015 and baseline (2012), both an absolute reduction and compared to matched facilities.

**Data and methods:** Primary analysis focused on hospitalizations for a retrospective cohort of 1975 nursing facility residents enrolled in OPTIMISTIC, starting at a single time point (October 2014) and followed for 90 days. Health and functional risk factors came from resident Minimum Data Set (MDS) assessments. Random effect logistic regression was used to model hospitalizations as a function of candidate risk factors. Supplemental data came from root cause analysis by project RNs for 1200 hospitalizations from October 2014 to December 2015.

**Results:** Ten percent of the cohort was hospitalized within 90 days. Statistically significantly risk factors and (Odds Ratios) were: hospitalization in the prior 30 days (4.74) or 31-90 days (2.23); history of cancer (2.52), COPD (1.52), anemia (1.42) or pressure sores (1.74); and receiving dialysis (3.58). Residents enrolled in hospice had a substantially reduced risk (0.12). Root cause analysis of hospitalizations found other contributing factors: dementia, behavioral problems, poly-pharmacy, and poor communication between nursing staff and medical providers.

**Application:** Findings are being applied in refinement of OPTIMISTIC's intervention strategies: targeting of high-risk residents for enhanced RN monitoring, APN interventions for hospitalized residents returning to the facility, medication reconciliation and poly-pharmacy review, advanced care planning, and special programs addressing behavioral problems and dementia.

**Policy implications:** Lessons from models of care, such as OPTIMISTIC, are shaping policy initiatives to reduce avoidable hospitalizations and promote better care for long-stay NF residents. Phase 2 of the demonstration project, which extends and expands on the clinical model, includes enhanced Medicare funding to medical providers and NFs to address changes in condition and prevent unnecessary hospitalizations.

## **How do people make decisions about ‘best’ and ‘worst’ quality of life states? A qualitative exploration of best-worst scaling responses to the ASCOT measure of care-related quality of life**

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*Thematic area:* Economics of long-term care

*Objective:* Multi-attribute utility measures, such as the Adult Social Care Outcomes Toolkit, are increasingly employed in the long-term care context to evaluate care. Stated preference techniques are often used to elicit preferences for the different quality of life states described by multi-attribute measures. Preferences provide an estimate of the value of each quality of life state and can be used as weights to combine responses in a way that reflects the differential utility of each state. To elicit preferences, newer measures, such as ASCOT, often use best-worst scaling (BWS), a choice-based technique derived from random utility theory. However, BWS has few applications and its acceptability, feasibility and validity – in terms of the extent to which decisions about best and worst states abide by the assumptions of utility theory -- are not well understood. The aim of this study is to provide a better understanding of the acceptability, feasibility and validity of the BWS technique.

*Data and methods:* We combine a BWS exercise with a qualitative approach known as verbal protocol analysis to explore the feasibility, acceptability and validity of the method for eliciting preferences for the ASCOT service user (ASCOT-S) and carer (ASCOT-C) instrument quality of life states. Validity is considered in terms of three axioms of utility theory: completeness, monotonicity and continuity of preferences. An adult sample (n = 20) undertook a BWS experiment involving either the ASCOT-S (8 people) or the ASCOT-C (12 people). The BWS experiment for both ASCOT instruments is based on a fractional-factorial design, consisting of 32 tasks, which were blocked into 4 segments. One task was repeated to test for completeness of preferences, meaning each participant undertook nine tasks. Respondents were asked to ‘think-aloud’ while completing the BWS tasks, but interviewers also used retrospective probing methods to generate a fuller understanding of the decision-making processes used. The transcripts were analysed using thematic analysis. Consistency of the repeated choice task was assessed quantitatively.

*Results:* Preliminary results indicate participants often used heuristics to aid their decision-making, for example by grouping attributes together or focusing on aspects they considered to be important to them. There was some evidence of non-trading behaviour, and some people may have been constructing their preferences as the task progressed, such as in different contexts. Respondents tended to be fairly inconsistent in their responses to the repeated choice task, being slightly more consistent with their best rather than their worst choices.

*Policy implications:* The increased level of interest assessing outcomes for long-term care means that measures like ASCOT are becoming more mainstream. The use of the BWS technique is still in its infancy in the field of health and long-term care. We consider how these results help provide insight into the value of BWS for eliciting preferences for multi-attribute utility measures like ASCOT. We also discuss how our study can inform the design of future BWS experiments in the field of long-term care and beyond. This indicator can help policy makers identify valued quality of life states, which can help guide commissioning policy.



## **Self-funders and long term care: selected findings from the SigN project**

***Kate Baxter***

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*Thematic area:* Personalisation of the care system

The SigN (Self-funders and Information Needs) project is a qualitative research study about the information needs of people in England who fund their social care from their own resources, often referred to as self-funders. By social care, we mean care and support provided in a person's own home or in a care home. The purpose of the study is to develop a resource for use by local council social care practitioners, general practitioners/family doctors, voluntary organisations and others who provide information and advice about social care to self-funders, as well as a short film and accompanying leaflet for self-funders about key information and advice issues.

Research evidence about people who pay for their social care is limited. Estimates of the proportion of self-funders in England vary, with some suggesting around a quarter of care in people's own homes and almost half of care home places are self-funded. Population ageing and rises in eligibility thresholds for local council-funded care means the numbers are increasing. The importance of self-funders to local councils is also increasing, in part due to new legislation in the Care Act 2014 which stipulated, among other things, that local councils must establish and maintain services to provide information and advice about social care to all local residents, not just those receiving care funded by the council.

For this study, we have carried out semi-structured interviews with 40 self-funders about their need for, experiences of and attitudes towards seeking information and advice about social care, and 19 practitioners about their contacts with self-funders, including typical questions and answers, and challenges in providing information. By the time of the presentation, we will also have interviewed five senior council managers about strategic level issues such as how the self-funding agenda sits alongside other priority areas; and facilitated workshops with self-funders and practitioners to help develop the project outputs.

In this presentation we will use selected findings from the SigN project to initiate discussion about local and national policies and plans around self-funders. The findings so far show that self-funders and their relatives can struggle to engage with social services; some feel that their status as self-funders leads to them being shut out of such services and denied information, while others were not aware that they had the option of approaching social services for advice or information. Issues covered will depend on those raised in interviews but are likely to include potential inequities between self- and council-funded service users, views on ways to engage people who are likely to be self-funders with local councils and other relevant services, and how other priority programmes of work sit alongside self-funding agendas.

## **Insights into the relationships among health support workers' work environments, work attitudes & work outcomes**

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*Thematic area:* Workforce and migrant workers

*Objective:* Health Support Workers (HSWs) are increasingly important for delivering care to vulnerable older Canadians in their homes and communities, and in long-term care facilities (nursing homes). In Canada, HSWs represent a significant component of the health care labour force. Approximately 100,000 unregulated HSWs work in Ontario; the majority (57%) work in nursing home/long term care (LTC) sectors, 34% work in home and community care (HCC) sector, while the remaining 9% work in acute care and other sectors. In the LTC and HCC sectors, HSWs provide up to 80% of the direct care to residents and clients. Despite their importance to elder care, as a workforce HSWs have received little research attention compared to the regulated professions. In Canada, as in many other jurisdictions, we have few insights into what factors influence HSWs' work attitudes – that is, their feelings about their work that manifest as job satisfaction, work engagement, organizational commitment, and the quality of their work life – or why they choose to work where they work. We know very little about how their attitudes toward work influence work-related outcomes, like performance and turnover. And while we know that work retention is a growing problem among HSWs, we do not know why some workers choose to leave their jobs while others elect to stay. Further, we know relatively little about the workers themselves including basic demographics, their wages and benefits, their training and preparation, and whether they consider themselves adequately prepared to deliver high quality care to their elderly clients - or, what they identify as gaps in their knowledge and experience. Our objective is to improve our understanding of the relationships among the work environments, work attitudes and work outcomes of HSWs engaged in caring for older Canadians in the long-term care and home and community care sectors.

*Data:* We report on findings from our analysis of 445 respondents to the Health Support Workers Work life Survey, administered to HSWs in the long-term care and home and community care settings in Ontario over Summer-Fall 2015.

*Methods:* We used PRELIS and LISREL to generate descriptive statistics of respondent data, conduct confirmatory factor analyses, complete a path analysis, and undertake structural equation modelling.

*Results:* The workforces in the LTC and HCC are similar in age, and most pursue more than one part-time job. LTC HSWs have on average a decade more experience than those in HCC and earn significantly more annually. Perceptions of work environments are generally favourable, although LTC workers feel less positive overall about their quality of work life than HCC workers, and HCC workers' perceptions of safety are significantly lower than their colleagues' in LTC. HCC workers have significantly lower scores for feelings of competence and organizational commitment, while LTC workers have significantly lower scores for feelings of autonomy and impact.

*Policy implications:* Beyond the differences between the two work forces in terms of worker characteristics and overall perceptions of work environments, work attitudes, and self-reported performance, our analyses suggest a number of levers within the purview of managers and health human resource decision-makers by which work attitudes and work performance might be influenced including through improving perceptions of safety and organizational support, and addressing aspects of quality of work life that are important to HSWs including actualization needs, knowledge needs, and economics and family needs.

## **A question of quality**

### ***Christina Bolger***

*Executive Director Programs and Education, Australian Aged Care Quality Agency, Australia*

Thematic area: Service commissioning and regulation

This presentation will describe how accreditation of aged care services is evolving alongside other tools such as outcome measures and consumer ratings as an instrument of better understanding the quality of care for older Australians. It will profile the challenges of quality assessment across diverse populations and a vast continent.

The Australian Aged Care Quality Agency (the Quality Agency) provides a framework for ensuring that all residential and home care services meet minimum standards of care. The accreditation system has set clear expectations for residential aged care and, over time, systems and practices improved and fewer and fewer residential aged care services failed to receive full accreditation or meet the Accreditation Standards.

The picture for aged care services is changing. An improvement in health means that older Australians are more likely to remain active for longer. People are choosing to stay in their own homes if the circumstances are right. This is reflected in the growth of home care services which are growing at 13% per annum (much higher than residential aged care). Performance against home care standards is variable, as services adjust to meet the challenges of a changing demographic and policy environment.

In the meantime, consumer expectations of quality in goods and services have grown. Consumers are now more empowered to determine for themselves what constitutes quality; and more adept at accessing and sharing information about the quality of services they receive.

Several changes are underway to improve aged care in Australia, to reduce regulation and to provide the individual with greater choice over their future. The Quality Agency has committed to work with the aged care sector to identify opportunities to improve the quality assessment and risk management system, and improve consumer participation in quality assurance processes. The question of quality is now live.

## **Long-term care in Quebec: so many issues to consider**

### ***Melanie Bourassa Forcier***

*University of Sherbrooke, Canada*

Thematic area: Service commissioning and regulation

The objective of the presentation is to point out the main issues surrounding long-term care in the province of Québec and to discuss the potential policy options that could help solving these issues: limited public insurance coverage, impact of the recent health care reform on access for specialized health care, issues regarding the respect of human rights, conciliation of public care and private life.

Limited public insurance coverage: In Québec, only elderly with high health care needs have access to public coverage for long-term care and housing. Therefore, only the elderly - with mid-health care needs – and covered by a private insurance have a decent and complete health care and housing access. A few years ago, it was proposed to create a public insurance specific to long-term care. This proposal was however rejected

by new government. We propose to revisit this proposal and to evaluate its viability with regards to the actual political and economic context in Quebec.

Impact of the recent health care reform on access for specialized health care: The recent health care reform in Quebec has merged a considerable number of health care facilities. Since then, long-term care for remote residents have been increasingly complex. We propose to point out the state of the situation and to evaluate what policy and legislative amendments should be considered in order to provide better long-term care for elderly.

Issues regarding the respect of human rights: The limited access to long-term care in Quebec is now rising concerns regarding its potential impact on the respect of some of the rights guaranteed by Canadian Charter, such as the 'security' right. In 2005, the Supreme Court of Canada, in *Chaoulli*, has granted a considerable weight to this right in the context of access to care. It is now pertinent to evaluate if the Supreme Court reasoning can, or cannot, be applied to the case of access to long-term care in Québec. In the affirmative, there would be an urgent need to rethink our long-term care policy.

Conciliation of public care and private life: Residents in long-term care public housing have different needs, including sexual needs. How can we conciliate these needs and the fact that these residents might not have the abilities, by themselves, to meet these needs? Should these residents be helped in meeting their needs? In the affirmative, what form this help might take?

Considering the legal background of the speaker, the presentation will focus on the laws and regulations surrounding these issues. An overview the legal implications of new policies for improving the state of elderly in the province of Quebec will also be provided.

## **Can social care reduce the risk of emergency readmissions of elderly people? Evidence from the linked health and social care data in Scotland**

***Feifei Bu***

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Co-authors: Alasdair Rutherford, University of Stirling; David Bell, University of Stirling

*Thematic area:* Health and social care integration

The past decade has witnessed a gradual increase in the rate of emergency hospital admissions in Scotland. It is estimated that around 53% of hospital admissions are emergency admissions between 2010 and 2011, while the emergency admission rate of older people is much higher compared with younger adults. This indicates a rising challenge for the public health system as the older population is projected to increase rapidly over the next a few decades. The aim of this study is to examine whether receiving social care will reduce the probability of emergency readmissions of older people, with a particular interest in the differences between people with and without dementia. Our data uses linked administrative health and social care records (2010-2011). It provides us a complete history of every patient's National Health Service (NHS) hospital admissions within a 12-month follow-up period, which can be linked with the information on social care usage collected by local authorities. Our analysis uses an extension of the Cox model, the conditional risk set model, which incorporates multiple events as a given patient could be readmitted more than once. We find no evidence that receiving social care reduces the risk of emergency readmissions for patients without dementia, or for patients who co-reside with others. However, our results have shown that receiving social care is an effective way of reducing the risk of emergency readmission for patients living with dementia and for older people who live alone. This population-based study provides empirical evidence that social care can play an effective role in easing the pressure faced by the health system. It offers valuable implications for the health and social care integration process carried on in Scotland and other countries in Europe.

## **Promoting participation of people with intellectual and developmental disabilities in social care research: Developing an Easy Read version of ASCOT**

**James Caiels**

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*Objective:* The Adult Social Care Outcomes Toolkit (ASCOT) is a standardised tool to collect data on social care-related quality of life. This paper reports the experiences of developing and cognitively testing an Easy Read version of ASCOT for self-report by people with intellectual disabilities.

*Data and methods:* The work combined survey development and pre-testing methods with approaches to creating accessible information for people with intellectual disabilities. A working group assisted researchers in identifying appropriate question formats, pictures and wording. Eight focus groups with 32 participants and 22 cognitive interviews were conducted to test various iterations of the instrument.

*Results:* As a result of feedback from the working group and findings from the cognitive interviews, a number of changes were made to the questionnaire, these included changes to illustrations, the wording of question stems and response options.

*Conclusions:* The process has demonstrated the benefits of including people with intellectual disabilities in the design and testing of data collection instruments. The research contributes to the aim of improving the engagement of groups that are under-represented in the evidence about social care.

## **Dynamics of social innovation and long-term care for elderly people: evidence based on case studies from Wallonia and Brussels**

**Ela Callorda Fossati**

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*Thematic area:* Other

*Objective:* This presentation explores the dynamics of social innovation in the 'sector' of long-term care for elderly people.

First, we consider the prevailing logics at the emergence of social innovation. To what extent the social problem solving rationale influences the creation of new and disruptive care services and forms to organise care work? Who are the social innovators and how do they involve in social innovative care?

Second, we examine the relevance of main models of scaling (duplication, diversification, cooperation, institutionalisation...) in order to explain real patterns in social innovative care initiatives.

*Data and methods:* Our analysis is based on empirical evidence from Wallonia and Brussels. Three main research methods are used.

First, case studies are identified and selected through the Delphi method. Indeed, a pool of experts participates in a consensus building process aiming to define the 'sample' of case studies. The 'sample' includes 14 cases (not for profit projects/organisations) from different care 'domains' (adapted housing, community based initiatives, respite care, accompaniment and psychological support, multidisciplinary approaches and technological social innovations). 3 of the 14 projects target issues related to the Alzheimer disease.

We combine two data collection methods in order to study the dynamics of social innovation. Documentary research gives us an indirect access of what happened at previous times along the social innovative process. We collect internal (legal status, annual activity reports, board resolutions, training and implementation manuals, subsidy application forms, newsletters, advertising...) as well as external documents (consultancy reports, press articles...). Our multidisciplinary research team (socioeconomics and public health) also conduct in-depth interviews with social innovators. We code both kinds of data, documents and interviews, in the same thematic template.

*Results:* Our preliminary results suggest that internal resources and proximity are key factors explaining the dynamics of emergence.

Patterns of scaling are diverse, non-linear and highly dependent on public funding and regulations.

*Policy implications:* Structural funding rather than facultative is urged by social innovators to be able to scale their social innovative care practices. Local public authorities (communes, provinces, régions) are particularly challenged by trends in social innovative care.

## **Building a tool to support the planning of long-term care networks under complexity: dealing with multiple objectives, uncertainty and policy strategies**

***Teresa Cardoso-Grilo***

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Multiple economic, demographic, epidemiologic and social changes are currently affecting European countries, posing extra challenges to the health care sector in general, and to the delivery of formal and informal Long-Term Care (LTC) in particular. Accordingly, policy-makers need to ensure that networks of LTC are responsive to population ageing and to an increasing prevalence of chronic diseases, as well as to make sure that scarce resources are adequately spent in LTC and that many policy objectives in the sector are pursued. This requires proper planning of LTC resources, which is specifically relevant for countries based on a National Health Service (NHS) that have been facing annual reductions in public health care spending. Planning of networks of LTC services is however a complex task, since the delivery of care is multi-service (comprising a combination of institutional, home-based and ambulatory services) and it is affected by health policies outside the LTC sector. Additionally, it is subject to uncertainty associated with the demand and the supply of care, and multiple objectives are to be attained by the delivery of care. Within this context, this study aims at building a comprehensive tool to aid policy-makers and health care planners making informed decisions on how to plan a network of LTC services under such a complex environment.

A planning tool based on optimization models is then developed so as to inform the planning of multi-service networks of LTC in the medium term, in terms of where to locate LTC services, how to plan capacities and to which patients deliver services. The tool is comprehensive by modelling the extent to which a LTC network accomplishes multiple, and often conflicting, policy objectives that are typically relevant for planners in the LTC sector, such as the maximization of health and wellbeing, the maximization of equity objectives (including equity of access, socioeconomic equity, geographical equity and equity of utilization), and the minimization of costs. The developed tool also considers how uncertainty in the demand and the delivery of care (for

instance, in the number of individuals needing care and in the length of stay of institutional services) and policy strategies outside the LTC sector (for instance, opting for institutionalized or community-based models of care) may influence the network of LTC services. Depending on the user of the tool: different objectives may be selected, the relative importance of these objectives may be defined; and alternative policy strategies may be set.

The applicability of the proposed tool is illustrated with a case study in the Great Lisbon region in Portugal, where a National Health Service (NHS) is in place. The obtained results allow for multiple analysis with the help of visual aids, including i) how and when to dimension existing and new services when different objectives are set, ii) which equity, health and wellbeing improvements can be obtained, and at which costs, and iii) how cost-effective may be different configurations of networks of care.

## **New evidence on the sustainability and inclusiveness of long-term care systems in Europe**

***Ludovico Carrino***

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*Thematic area:* Equity and efficiency

The extraordinary improvement in life expectancy and health conditions experienced in the last century in many developed countries has profoundly changed the demographic structure of Western societies. As result, the rate of care-dependent older people in need of Long Term Care (LTC) is estimated to rise, while the expected increase in the LTC workforce is rather modest. In this context, the economic relevance of formal LTC has been growing. Recently adopted policies in major developed countries identified new forms of community- and domiciliary-care as sustainable approaches that could prevent institutionalization, while easing the burden of care on family members, preventing the generation of 'care gaps', under binding public budget constraints (Gori & Fernandez, 2015).

In this paper we investigate the sustainability of public LTC systems in several European countries in the forthcoming decades, using the European Union Future Elderly Model (EU-FEM), a dynamic microsimulation model which project the health and socio-economic characteristics of the European population 50+, augmented with information on the eligibility rules and costs of major current home-care systems.

In particular, we first analyze and compare the inclusiveness levels of current major national and regional European programs of home elderly-care, both in-cash and in-kind, by focusing on eligibility and assessment rules. Indeed, even if most programs evaluate 'objective vulnerability' on a set of functional (mostly ADL and IADL tasks) and cognitive limitations, almost no regulation includes them homogeneously in the assessment process. This leads to important differences on programs' inclusiveness levels, which have not yet been comprehensively covered in the literature. By combining the micro-data dimension with a set of institutional-level information on LTC regulations, we are able to build, for each individual, a simplified socio-medical profile comparable with the requirements of the LTC programs. Finally, we use this information as input in the microsimulation model to construct 'what if' scenarios that will shed light on the long-term sustainability of the LTC systems.

The empirical analysis is based on micro-data on elderly individuals from SHARE, thus accounting also for the existing heterogeneity in morbidity rates across limitations and across countries. The use of individual level data allows to have a better understanding of the trends in the demand for LTC differentiated by age groups, gender, and other demographic and social characteristics in order to better assess the distributional effects. This is particularly important because, although on average we live longer and in better health, several

studies have identified large degrees of health inequality among socio-economic groups (e.g., Case & Deaton (2015)). Furthermore, this novel approach allows also to better understand the effectiveness of such simulation models for LTC, a feature that the economic literature has often highlighted as extremely important when conducting empirical analyses.

As a result, we estimate the future potential coverage (or gap of coverage) of each national/regional public home-care system, and then disentangle the differences between countries in a population and a regulation effects. Our analysis offers new insights on how would the demand and the public/private expenditure for LTC evolve over time, what would the distributional effects of different LTC policies be if no action is taken, and what could be potential impact of alternative care policies or innovations.

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## **Case management as social innovation in long-term care: lessons from the Italian** **Georgia Casanova**

Country: Italy

INRCA - National Institute of Health & Science on Ageing

Co-authors: Giovanni Lamura, INRCA - National Institute of Health & Science on Ageing  
Andrea Principi, INRCA - National Institute of Health & Science on Ageing

*Thematic area:* Case management

*Background:* In the last decades the debate on policies to address the challenges posed by population aging has led to a change in the approach used to tackle this issue, paying more attention to the impact this phenomenon might have on society and on lifestyles along the life course (Leichsenring et al., 2013; Walker & Foster, 2013). This includes the widespread use of keywords such as 'active ageing' and 'social innovation' in formulating policies, thus underlining the emergence of innovative strategies to face the new challenges deriving from changes in sociodemographics and societal needs (European Commission 2012). In the Long-Term Care (LTC) sector, social innovation has been focussing on attempts to improve the quality of life of frail older people and of their informal caregivers. Although many good practices have been activated in this respect, no systematic review of these experiences has yet been carried out to understand what are the main barriers and drivers of social innovation in this field, and to promote the mainstreaming of prototypal actions into systematic change. In a recent study on the Italian context (Schulmann et al. 2015, Van der Heide et al 2015) however, case management has been identified as one of the main social innovations observed, involving many important elements for LTC development: multidisciplinary staff, integration between health and social care, stakeholders coordination, ICT support.

*Objective:* This presentation aims to illustrate why case management represents one of the main social innovations implemented in the Italian context, what are the policy sectors involved and which further steps are more urgently needed in the future.

*Data and methods:* Starting from the findings reported by the research carried out within the MOPACT project in the field of LTC (<http://mopact.group.shef.ac.uk/research-fields/social-support-and-long-term-care/>), this presentation is based on the systematic review of Italian data collected via national focus groups, experts interviews and case studies. The study considers drivers, barriers and transferability as key dimensions of analysis, and the micro, meso and macro dimensions as a tool to elaborate policy recommendations.

*Results and policy implications:* Case management represents a social innovation promoting a paradigmatic shift in LTC delivery, from acute care to prevention and from a system-centred to a user-centred approach.



‘Integration’ and ‘coordination’ become key in this respect, as does the focus on shared skills and responsibilities among all stakeholders (professional and informal carers, local actors and institutions). Although LTC fragmentation represents still a main barrier to the implementation of this approach in Italy, the existence of local experiences in this area underlines some promising perspectives for their scaling-up in this country. To this purpose, however, following strategies become crucial: to facilitate the transferability of experiences (e.g. by supporting the collaboration of micro-level initiatives into meso-macro level networks); to disseminate ICT use as a key-driver to improve quality care and working conditions; to promote interprofessional, inter-institutional and inter-stakeholders collaboration; to strengthen the development of a LTC system identity that includes prevention as a key component.

## **Technology skills for the long term care sector: developing a research agenda** **Bernard Casey and Paul Freddolino**

*London School of Economics, United Kingdom and Michigan State University, US*

*Thematic area: Technology and long-term care*

While we can be fairly certain that the global trend is for increased longevity and concurrently increased numbers of people living with chronic health conditions and needing long term care, the potential impact that emerging technology may play in coping with these trends is much less understood. One aspect of technology’s impact on the long term care sector could come in the form of technology that changes the mix of formal versus informal care, or the mix of institutional versus in-home care. A related but different aspect is the impact of technology on the productivity of workers in the formal care sector, an issue that becomes increasingly important with recognition of the constraints on the supply of labour for these formal care roles.

The proposed presentation will identify some of these emerging issues, report on relevant preliminary research, and identify a research agenda to address the major unknowns in the field. Developments in the care sectors in Germany and Japan highlight very different trends that suggest themes that require further attention. Both countries face rapid ageing and labour force constraints. Both have sought to upgrade the care workforce. But, whilst Germany is still reliant on using non-professional (often foreign) workers, Japan has tried to make use of new technology to deliver physical assistance and even supplementary services, such as attention and communication, to recipients of long-term care. How to incorporate greater use of technology into long term care services, and the potential impact of greater technology use on attracting and retaining a qualified work force, will also be addressed.

## **The working experience of care workers in the long-term care insurance in Korea** **Yongho Chon**

*Incheon National University, South Korea*

*Thematic area: Workforce and migrant workers*

South Korea introduced a compulsory long-term care insurance in July 2008. The aim of the research is to understand the reasons of turnover of care workers. The research question of the study is ‘Why do care workers are likely to move to other service providing organizations or resign their jobs?’

To explore the issue, the author conducted semi-structured in-depth interviews with 20 care workers in South Korea.

The care workers actively reported their experiences of the provision of services in the field. The interview participants not only shared their own intention of turnover, but they also frequently reported the experiences of other colleague care workers who moved to other organizations or resigned their jobs altogether. Overall, it was found that the turnover of care workers is related with a number of inter-related factors. Namely, the turnover issues are related with not only the macro level factors such as social

perception on care workers, but also the meso level factors such as organizational management and the micro level factors such as the relationships with care workers and other people.

## **Policies of user participation: the case of older people and social care in Norway and England**

***Karen Christensen***

Country: Norway

*University of Bergen*

Co-authors: Doria Pilling, City University London

*Thematic area:* International comparative analysis

User participation has become one of the most important concepts in the social care sector in both Norway and England; increasingly this is presented as a goal when designing the services. While there has been much emphasis on user participation in literature related to disabled people or those with mental health problems, this is a neglected subject in relation to older people. The objective of our study is to specifically investigate and compare the policies of user participation directed at older people in the social care sector in Norway and England. The comparison is particularly relevant because these two northern European countries represent two different welfare regimes: one 'social democratic' in the case of Norway, and in the case of England increasingly a 'liberal' type from the time of the Conservative government at the end of the 1970s.

Although the formal basis for change in social care policies are government policy documents, setting out proposals for future legislation, they are rarely analysed per se. We will analyse such national policy documents, primarily a selection of White Papers from the 1960s until today, using a discourse analytical approach inspired by Bacchi (1999). Our historical comparison of Norwegian and English discourses about user participation will be related to the different discourses discussed in the research literature; particularly the distinction between a 'democratic/rights based' one and a 'consumer-oriented one'. The democracy rationale comes from the right of individuals to control their own lives, as full citizens in society. It is about influence on policy development, resource allocation and governance. The consumer rationale views the individual user as a consumer of services, who should have the right to choose for example from a market of service providers. Additionally, also a discourse about co-production, underlining partnership between the user and state/local authority is currently discussed.

Our analysis will show how these different discourses appear in our selection of national policy documents over time, but with a time difference as well as a difference in strength and type of presentation in the two countries. In both countries, however, there is a change towards a stronger emphasis in expecting people to remain active, independent and connected to their communities to delay or prevent the need for social care.

## **Sports and reminiscence: the rationale and evidence for its use to build social connections for older people**

***Michael Clark***

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*London School of Economics & Political Science*

Co-authors: Charlie Murphy, Independent training and evaluation consultant

Tony Jameson-Allen, Director, Sporting Memories Network

Chris Wilkins, Director, Sporting Memories Network

*Thematic area:* Other

*Background and objective:* Sports represent a powerful strand of memory and identity for many individuals, and a rich stream of shared cultural heritage. Sports-based reminiscence aims to draw upon this resource to connect people and to address some needs amongst (usually) older people. This may be connecting people

living with dementia to their care staff or others, or bringing together older people who are, or are at risk of becoming, isolated, and other patterns of social bonding. The intention is that this can help to address some of the challenges societies face from dementia and from issues of loneliness and isolation amongst growing populations of older people. This paper will discuss lessons from experiences of using sporting memories in this way and sets out some implications for policy and further research in this area.

*Data and methods:* Initially we examine the rationale for sport-based reminiscence in various contexts. We proceed to discuss the evidence of its use in practice. Sporting memories has operated in many contexts, including care homes, community-based dementia services and in sports clubs. We draw on a range of evidence collected from these contexts using questionnaires, participant observation and interviews.

*Results:* We identify different forms of using sporting reminiscence to suit diverse contexts and needs, and for different ends. These include variations on more formal approaches to group work and to one-to-one work, and an ad hoc mode. We discuss the experiences of those trained in using the approach and their perceptions of its power. For many people sports-reminiscence is very focused on specific sports, clubs, events and/or personalities. It has the power, however, to transcend this and become a means of engaging in discussion about wider social and family history and, thereby, engage with and connect a larger network of older people.

*Policy implications:* Sports-based reminiscence represents an approach to engaging with people that is very flexible (it can be used in many ways and in diverse contexts) and highly personal (it draws on some of their key memories and identity). It has the power to connect people and thereby address some of the challenges societies face from ageing population profiles. The flexibility of sports reminiscence means that there is a need to take care in being clear as to the modes of engagement and desired outcomes being used in any specific project/setting. There are still research questions that need to be addressed in order to more fully develop the evidence-base to guide practice.

## **Family spillovers of long-term care insurance**

***Norma Coe***

*University of Washington, United States*

Co-authors: Gopi Goda, Stanford University; Courtney Van Houtven, Duke University

We examine how long-term care insurance (LTCI) affects family outcomes expected to be sensitive to LTCI, including utilization of informal care and spillover effects on children. An instrumental variables approach allows us to address the endogeneity of LTCI coverage. LTCI coverage induces less informal caregiving, suggesting the presence of intra-family moral hazard. We also find that children are less likely to co-reside or live nearby parents with LTCI and more likely to work full-time, suggesting that significant economic gains from private LTCI could accrue to the younger generation.

## **Key issues and challenges in long-term care organization and financing in differently resourced countries: from service coverage to sustainability**

***Adelina Comas-Herrera***

*London School of Economics, UK*

Co-authors: Martin Knapp, Emily Freeman, Flora Zheng, Cynthia Blick, Bo Hu, Elisabeth Schröder-Butterfill, Mariana Lopez-Ortega, Anna Rupert, Nanjoo Yang

*Thematic area:* LTC in LMIC countries

Ageing is a global phenomenon but is happening at different speeds in different countries. In most high-income countries the ageing process has happened over a long period of time, and alongside sustained economic growth, which has enabled those countries to gradually develop the policies and infrastructures needed to adapt to the health, care and other needs of an older population. In low- and middle-income

economies, and some countries that have reached 'high-income' more recently, the ageing process is happening at a much faster pace than that experienced by the more 'traditionally old' countries.

The degree to which the growth in the numbers of older people is accompanied by economic growth will have a major effect on how well placed countries will find themselves to support the development of long-term care systems that can adequately meet the needs of growing populations with care needs. The models of care that have emerged in the 'slow ageing' high-income countries may not necessarily be the right ones for countries that are ageing at high speed and with fewer resources.

This paper, produced for the World Health Organisation Working Group on Long Term Care Systems, considers the key policy issues and challenges for the financing and organization of long-term care in Canada, China, England, Kenya, Indonesia, Mexico, South Africa and South Korea. While these countries have very diverse demographic, social and economic contexts, there are common policy concerns with regards coverage access to care in rural areas, equity in relation to financing, gender inequality, sustainability, supporting carers, ensuring workforce capacity, improving care coordination, regulation and quality of care.

## **Modelling dementia care pathways in low, middle and high income countries** **Adelina Comas-Herrera**

*London School of Economics, UK*

Co-authors: Martin Knapp, Emily Freeman, Cynthia Blick, Kaeyun Park, Ruru Ping, Anna Rupert, Maria Lopez, Mariana Lopez, Maelenn Guerchet, Maria Karagiannidou, Martin Prince

*Thematic area:* Dementia and care

While dementia is often seen as a problem of the developed world, the numbers of older people are increasing rapidly in low- and middle-income countries, which is resulting in huge rises in the numbers of people living with dementia. In the context of the need for countries to adapt their existing care pathways, or to start developing a service infrastructure to meet the needs of people with dementia and their families, this presentation will report on a project that explores what would be the economic impact of implementing evidence-based dementia care pathways in Canada, China, Indonesia, Mexico, South Africa, South Korea and Switzerland by 2030.

The project consists of three parts. The first part involves a review of the literature on care pathways which will result in recommendations of care pathways for low-, middle- and high-income countries, distinguishing between pathways for those with mild, moderate and severe dementia.

The second part of the project involves describing the current dementia care in each of the countries, including the demographic, geographical and economic contexts, and also the health and social care systems through which care and treatments are delivered. Simple simulation models will be built for each of the countries, in order to show the impact of demographic change in the future numbers of older people with dementia, their use of health and social care, and the costs of that care.

Finally, the models will be used to simulate the impact of implementing better care pathways, considering in particular the coverage of services that would be required and the costs of those services, assuming that the care pathways would be fully implemented by 2030 and will simulate a stepping-up process from the current levels of care in five year intervals.

## **The MODEM Project (a comprehensive approach to MODelling outcome and costs impacts of interventions for DEMentia)**

**Adelina Comas-Herrera**

*London School of Economics, UK*

Co-authors: Martin Knapp, Raphael Wittenberg, Ann Bowling, Sube Banerjee, Emily Grundy, Carol Jagger and the MODEM team.

*Thematic area:* Dementia and care

*Background:* The MODEM project (A comprehensive approach to MODelling outcome and costs impacts of interventions for DEMentia) explores how changes in arrangements for the future treatment and care of people with dementia, and support for family carers, could result in better outcomes and more efficient use of resources.

*Methods:* The MODEM team has conducted a systematic mapping of the literature on effective and (potentially) cost-effective interventions in dementia care. We are using those findings to model the quality of life and cost impacts of making these interventions more widely available in England over the period from now to 2040. We are using a suite of models, combining micro and macrosimulation methods, modelling the costs and outcomes of care, both for an individual over the lifecourse and for individuals and the country as a whole in a particular year. The MODEM project concludes in 2018; we will present intermediate outcomes from the evidence review and the lifecourse model.

*Results:* Current costs of dementia in the UK are around £21 billion, but those costs could change with wider availability of cost-effective care and support. If medications to alleviate the symptoms of dementia were available to everyone with Alzheimer's disease, savings could be c.£250 million in overall costs, comprising a saving of c.£400 million in social care with a partially offsetting extra cost of £150 million for unpaid care. If cognitive stimulation therapy was delivered to everyone with mild/moderate dementia, there would be little difference in overall costs, with a slight shift from social care to health care costs. Finally, if family carers of people with dementia were supported with the START coping intervention, overall costs would be c.£200 million higher than they are today, comprising savings of £200 million on health and social care and an extra £400 million in unpaid care costs. There would however be significant improvements in caregiver quality of life.

*Conclusions:* Making cost-effective interventions more widely available has the potential to reduce costs of care and improve the quality of life both of people with dementia and their family caregivers.

## **Direct payments support in England: the hidden face of direct payments**

**Vanessa Davey**

*London School of Economics, UK*

*Thematic area:* Unpaid carers

Personal budget holders in England choose between opting for the local authority to commission the services they require on their behalf (a managed budget), or directing the arrangement themselves by taking their budget in the form of a direct payment, or a combination of the two. Direct payment users may choose to purchase services from within the formal social care sector (such as a home care agency) or from a personal assistant, or purchase equipment that they are assessed as requiring. Where a direct payment (DP) is the preferred option but a person lacks capacity to manage it, a recognized 'suitable person' may be granted permission to act as a proxy. Whether managed by the service user or a suitable person, DP management requires completion of core administrative tasks and other skills related to securing and supervising care. Since DPs were first introduced, external direct payments support (DPS) has been an integral part of the model, provided by entities referred to collectively as Direct Payments Support Schemes (DPSS). A decade

ago, amidst a major policy drive to promote DPSS, the sector expanded significantly. As a result, by 2007 almost every council in England had a contractual agreement with a DPSS provider. This provider group was surprisingly heterogeneous, ideologically centered on User-Led Organisations (ULOs) and Centres for Independent Living (CILs), but actually composed of a variety of organisations ranging widely in their size and scope of services, albeit mainly voluntary organisations. As take-up of DPSS grew, pressure mounted on local authorities to support an increasing user-base, both in number and in diversity. By 2010, significant turnover in DPSS was being reported. Concerned service users, DPSS staff and members of the independent living movement suggested that DPSS run by CILs and other ULOs were increasingly being decommissioned, whilst other organisations were growing, offering lower-priced services but less direct contact with service users. We set out to determine the extent of turnover from our database of organisations responding to the PSSRU national Direct Payments Survey (2007). We started by exploring the original data to establish if the variation in services provided was patterned and if it was linked to characteristics of organisations. Five profiles emerged offering very distinct models of DPSS. When we related the profiles to organisational characteristics a less clear-cut relationship between organisation type and service profile emerged than had been anticipated, for example there was no obvious CIL profile. To monitor turnover, we tracked the original sample in 2011 in 2014, observing changes in provision. With this data we explored how affinity to a certain service profile may have affected organisations' staying-power. The results provide insight into the evolution of this market over the past decade, demonstrating the influence of local authority preferences on the delivery of DPSS and the impacts of service viability, revealing a hidden face of DP with significant implications for service users.

## **A capabilities approach to standard of living and disability costs in older people in the UK**

***Elaine Douglas***

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*Thematic area:* Economics of long-term care

Standard items of material deprivation, such as having a warm winter coat or taking a holiday each year, used as a measure of standard of living may be problematic when applied to older populations. Evidence suggests that older people are less willing to state they cannot afford items or are under financial strain (Groffen, Bosma, Van Den Akker, Kempen, & Van Eijk, 2008; Grundy & Holt, 2001; McKay, 2004). Further, how 'standard of living' is valued is not homogenous and is likely to vary according to context and population (Coast, Kinghorn, & Mitchell, 2014) and therefore may change at different stages of life. This suggests that methods to assess standard of living that utilise prescribed measures of material deprivation, including what people can or cannot do in relation to financial affordability, are limited when evaluating the standard of living in older people. Yet, maintaining a valued standard of living is of particular importance to older people as they negotiate changes in both their financial and health resources as they age.

The objective of this study was to implement Sen's Capabilities Approach (Sen, 1985) to standard of living to estimate older people's disability costs in the UK, based upon a similar approach taken by Morciano, Hancock, & Pudney (2015). We aimed to broaden current evaluations of standard of living to include what older people can do (freedom of choice), rather than what they actually do (functioning). This study also aimed to tackle some of the methodological challenges associated with translating such theoretical concepts into practical, policy relevant applications.

Using data from Understanding Society and the Family Resources Survey we produced a framework of capabilities based upon older people's values in relation to standard of living. This framework comprised five core values: Social Integration (attachment); Security; Contribution (Role); Enjoyment; and Control

(Autonomy/Restriction) as developed in the ICECAP-O (Investigating Choice Experiments Capability Measure in Older Adults, Coast et al., 2008) and LSCAPE (Living Standards Capability for Elders, Breheny et al., 2013, 2014). Data items from each survey were attributed to the five core values to construct a latent variable of capability. Using a latent factor structural equation model we estimated the extra cost of disability for a representative sample of older people in the UK.

The use of Sen's capability approach, within a framework of older people's values, offers a broader set of outcomes for policy. For example, targeting older people's capabilities may have a more practical application and offer a more effective means to measure the benefits from policy intervention. This approach shifts the focus of policy towards older people's ability to attain a valued standard of living, rather than on whether they can achieve, or can afford, certain prescribed functions.

## **The marketization of long-term care policies – explaining differences in the reform pathways in conservative welfare states**

***Thurid Eggers***

Country: Germany  
*University of Hamburg*

Co-authors: Birgit Pfau-Effinger, University of Hamburg  
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*Thematic area:* Institutional dynamics and politics

Since the 1990s, many welfare states have extended social expenditure and social rights in Long-term Care (LTC) policies for senior citizens. At the same time they have also strengthened market principles in LTC policies. There are substantial differences concerning the forms and strength of marketization between European welfare states, even between welfare states with similar characteristics. So far, empirical studies are rare that explain cross-national differences in LTC marketization.

This paper aims to explain differences in LTC policy marketization between two conservative welfare states, Germany and Austria. Both have experienced a paradigmatic policy change in LTC policies in the 1990s, which combined the extension of publicly paid social services and new social rights with a strengthening of market principles. However, the LTC policy marketization was clearly more far-reaching in the Austrian welfare state compared with the German welfare state.

We use the 'welfare arrangement' approach by Birgit Pfau-Effinger (2005) for an explanatory framework. It emphasizes the role of cultural change and socio-economic change and of the development of power relations and actors constellations in the context of historical development paths for the explanation of cross-national differences regarding welfare state reforms. The empirical study is based on the analysis of the different development paths, in which the policy reforms were embedded, and the causal relations and processes on which they were based. It uses methods like public statistics, document analysis, and secondary analysis of qualitative empirical studies.

The findings show that the differences can mainly be explained with differences in the role of market elements in the previous care policies and in the main cultural ideas that were relevant in the policy process. The paper provides an innovative contribution to the international comparative theory and research about historical change in welfare state policies.

## **Stories of disease and treatment: organizational models for continuity of care**

### ***Giovanna Ferretti***

Country: Italy

*Studio APS*

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*Thematic area:* Care models

Chronic diseases need ongoing care. The paradigm of continuing care requires organization that facilitates integrated interventions among the various community and hospital-based services and which minimizes the fragmentation of care. There is a need to create a unified system of medical and social services to coordinate all the existing organizational entities and assure continuity of care.

The study proposes to improve the continuity of care in fragile, complex patients with chronic diseases by providing indications that favor the diffusion of the most efficient organizational practices. In the study the patients and health professionals together define a territorial organizational model for both efficacious and efficient continuing care. It is a pilot study which could be broadened beyond the areas studied to have an impact on health care organization more generally.

Qualitative research was conducted in two urban centers in northern Italy (Brunod, Manoukian in Colucci, 2008). It analyzed the organizational models capable of providing both efficacious and efficient care from the perspective of patients and their health care professionals. Interviews with fragile, complex patients (Barthel 3) - excluding oncologic and psychiatric patients - served to identify pathways to care from one service to another. It analyzed cultural models already in use by health professionals and the ability of patients to understand the pathways formulated on the basis of their disease characteristics and functional status; the organizational variables and the control of decision-making processes between territory and hospital.

The study produced an analysis of existing organizational models, a comparison between territories and setting of care, and the input of patients and health professionals. It identified weak points as well as effective organizational processes which helped to maintain communication among the various figures involved the the continuing care process. As well it helped to discover innovative and original methods of intervention and to foreshadow some organizational models capable of firmly overseeing processes of care between hospitals and territories and between families and local services.

The Italian National Health Service, founded on the concept of universality and at no cost to patients today is changing both for epidemiologic reasons (WHO Europe 2014) and for better allocation of resources, as well as new guidelines in cost standardization. An organizational change is required in the direction of greater efficacy and efficiency in terms of continuity of care and assistance. At the regional level the recent reforms in the health care and social assistance sectors have resulted in a shifting of health care and social assistance services from hospitals to the territories in a system not yet sufficiently organized or ready to assume care of a clientele in a form different than that offered by hospitals, either acute care or long-term. In consideration of the epidemiologic data and the reduction of resources at the national level a trend toward territorial health care has appeared (Gori, 2014). This study highlights other dimensions that make an impact on the development of an efficacious and efficient health care policy.



## **Use of long-term care is increasingly concentrated in the last years of life – a comparison of old decedents and survivors from 2000 to 2011**

**Leena Forma**

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*Thematic area:* Economics of long-term care

*Objective:* Use of long-term care (LTC) is concentrated in the very old age and in the last years of life. As the deaths are postponed to increasingly old age, more people will probably use LTC in their last years of life. Aims of the study are to analyse the association of use of round-the-clock LTC with approaching death among old people and the change of this association from 2000 to 2011.

*Data and methods:* The data were derived from national registers. The study population consists of 315 458 case-control pairs. Cases (decedents) were those who died between 2000 and 2011 at the age of 70 years or over in Finland. Controls (survivors) lived at least two years longer. The pairs were individually matched for age, gender and municipality of residence. Use of LTC was studied for the last 730 days for decedents and for the same calendar days for survivors. Conditional logistic regression analyses were performed to test the association of LTC use with decedent status and calendar year.

*Results:* The difference in LTC use between decedents and survivors was smallest among the oldest, for use of LTC is high among old survivors, too. In the total study population the use of LTC increased from 2000 to 2011 both among decedents and survivors, for the proportion of the oldest, whose use is highest, increased remarkably. The difference between decedents and survivors widened from 2000 to 2011 in all age groups: use increased among decedents in younger age groups, held steady among the oldest but decreased among survivors in all age groups.

*Policy implications:* The association of approaching death with use on LTC became stronger from 2000 to 2011. That is, use of LTC was increasingly concentrated in the last years of life during the twelve-year study period. Use of LTC is common among the oldest, despite the closeness of death. As more people live to a very old age, the demand for LTC will increase.

## **Elderly care and the value of sharing economy. What can we learn and bring to the care sector from sharing economy initiatives?**

**Giovanni Fosti**

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*Thematic area:* Personalisation of the care system

*Objective:* Sharing economy is becoming a worldwide issue. The transition towards collaborative economy is investing many sectors and many targets groups. The sharing perspective can be easily applied to welfare initiatives, where the concepts of giving and sharing are innate and go hands in hands with caring. The public sector is becoming aware of the potential of the sharing economy (i.e. in the UK, Woskowsky, 2014), both for its economic development force and social impact. Could elderly care and long term care benefit from this perspective? Some attempts have been made about it (Ranchordás, 2015) but no systematization has been provided yet. In sharing economy services, elderly people can act as both end users and givers (sharers). At the same time, shared services for the elderly can be oriented towards care initiatives or, more broadly, towards social inclusions or active ageing activities. Many bottom up solutions are emerging around Europe (Wagner et al., 2015) and a growing attention is needed to evaluate its possible contribution to answer needs and provide innovative solutions (also with an impact on future financial sustainability). Our work offers two main contributions: first we try to systematize how the sharing economy model can be applied to long term care and which may be its support in innovate the sector; second we sketch some good examples of sharing economy initiatives used by and for the elderly.

*Data and methods:* Going through a review of the existing evidences about sharing economy, we provide a general framework to translate the main concepts in the long term care sector. This is helpful to highlight strengths, weakness, opportunities and threats and to sketch the possible contribution in the LTC sector. We use our framework to map some existing experiences of collaborative services for the elderly around Europe. We collect data and information through official reports, websites and secondary sources, since poor research has been done since today on these topics.

*Results:* The existing experiences show that sharing economy services won't substitute traditional care services but they can contribute to active ageing efforts and supportive care services.

*Policy implications:* Sharing economy is a good possibility to promote innovation in the LTC sector and, more broadly, in the welfare sector. Sharing economy, of course, is not the way to solve welfare issues that western countries are facing today, but it can help to promote a more inclusive society and to provide welfare services to a broader group of citizens.

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## **LTC reform trends between national and local policies: insights from Italy**

**Giovanni Fosti**

Country: Italy

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*Thematic area:* Local vs. central policy interactions

*Objective:* Long term care is an hot topic around the world. A wind of change and reform is passing through the western countries, since the financial sustainability and the demographic issues are challenging traditional welfare states policies. Main LTC reforms at the national level have touched three traditional pillars (funding, carers and institutional settings) with different levels of success and failure (Gori & Fernandez, 2015). If national government are working hard on these issues, a lot is going on also at the local level, where the attention is more on services and care features then on broad policy issues (Lechevalier et al. 2013). Here, LTC reforms deal more with innovation and transitions in care settings and new ways of involving citizens and users.

Our work offers a picture of what is going on in Italy in terms of LTC innovation and reforms at the local level. We provide an overview of trends in the care sector, reviewing what has been 'proposed' as innovative and new, in regional and local policies. We first analyse what happened in the last 2 years in the 20 Italian regions; then we focus on a specific region (Lombardy) to find out what happened at the local level by analysing the strategic plans and policy documents of social care districts for the same periods. Similarities and differences between the regional and the local level emerge, together with a general insight of LTC policy changes in Italy.

*Data and methods:* Starting from a general assessment of Italian LTC reforms at the national level between 2014 and 2016, we move to the regional level by analysing regional reports and policy documents: we perform a desk content analysis looking through regional official documents related to LTC policies to map every possible sign of reform. In this work we use the word 'reform' to point out every new policy trend or change compared to previous policies features (i.e. different funding system, new services, different access criteria, ...). For what concern the local level, we benefit from the strategic process that involved the 98 social care districts of the Lombardy region in 2015, when they were enrolled in a three years planning initiative. We analyse the strategic and policy documents they produced, in order to map innovations and changes they proposed when defining future local LTC policies.

*Results:* Our analysis show that when speaking about 'changes and reforms' the national, regional (or intermediate) and local level point out different issues and proposal. Moving from the national to the local level, they shift from a pressure on funding to the importance of innovation and quality of services. The Italian insights we provide is also useful to map innovative ideas and services for the elderly.

*Policy implications:* Our work is useful both for Italian and European policy makers, since it provides a general picture of trends and future challenges for the LTC sector.

[1] Gori, C., & Fernandez, J. L. (2015). Long-term Care Reforms in OECD Countries. Policy Press.

[2] Lechevalier, A., Giraud, O., & Kumpers, B. (2013). Policy learning and innovation in local regimes of home-based care for the elderly: Germany, Scotland and Switzerland (No. halshs-00788968).

## **Technology tools to support people with dementia and family carers**

***Paul Freddolino***

Country: United States

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*Thematic area:* Technology and long-term care

Around the globe, anticipated increases in people with dementia will mean more individuals directly affected by the side effects and symptoms, and more people serving as unpaid family carers. Among people with dementia there will be variation in needs due to the specific type of dementia involved, and to the stage or severity of symptoms. These in turn will have an impact on family carers. Often vulnerable and at risk themselves, whether they be spouses, children, or others, carers frequently find themselves with little support or attention to their needs, even from those agencies providing services to their loved ones.

Relatively new resources to support people with dementia and family carers come from the expanding range of technology tools and technology-assisted services now available and under development. Ranging from simple remote sensors to somewhat exotic avatar-based 24/7 services, these new tools promise increased learning and information, 'how-to-handle' resources on demand, greater safety and security for the loved one, reduced carer stress and burden, increased independence and time at home for the patient, reduced hospital and medical costs for patients and carers, and improved quality of life.

Based on data collected through scoping studies in several countries, this presentation will 1) review the range of technology tools and technology-assisted services available to patients and carers at different levels of severity and different stages of the long term care journey; 2) summarize the available evidence regarding the effectiveness of these tools; and 3) describe some of the challenges that must be addressed to provide both better information about effectiveness and broader utilization by the very people with dementia and carers who need them.

## **The future of long term care for vulnerable older adults in South Africa**

***Emily Freeman***

Country: United Kingdom

*London School of Economics*

*Thematic area:* LTC in LMIC countries

*Background:* The number of care-dependent older adults in Sub-Saharan Africa is expected to rise dramatically over the next 30 years. In countries with limited private or public sector provision of long term care this will place growing pressure on families. However there are already profound inadequacies in familial care provision due to major economic, mental and physical caregiver strain. Subsequently, ageing has been identified as a significant risk to development by governments across Africa. While policy makers continue to look to families as the primary providers of care for older adults, more attention is being paid to new alternatives of care, including formal, non-familial long term care providers, facilities and services. This attention is not all positive however, with key stakeholders (albeit excluding older adults) raising both economic and cultural challenges to non-familial care models. The paper presents work from a broader project exploring how formal provision of long-term care for vulnerable adults aged 50+ can be reconciled with informal provision in order to plan interventions that can meet the care needs of growing populations of older adults in Africa.

*Data:* The paper focuses on experiences in South Africa, where social, demographic and health changes mean that population ageing and increase in the size of the older population are significant, some older adults are especially vulnerable to unmet needs for long term familial care, and an expansive range of formal care is available (for some). This case study provides an in-depth examination of older and younger adults' and organisational stakeholders' attitudes to, and experiences of, care in older age.

*Objective:* The objective of this paper is to establish a nuanced understanding of perceptions about providing formal and informal care for older adults and the challenges of providing formal care to older adults. It will do this by seeking to understand what older adults in need of long-term care themselves feel about informal and formal provision and whether informal carers and potential informal careers would welcome formal support.

*Methods:* Fieldwork will be carried out in contrasting Gauteng and KwaZulu-Natal provinces. In each setting data will be generated using repeated in-depth qualitative interviews with:

- older adults receiving formal care (residential care, day care and home-based care) (n~30);
- older adults with functional limitations receiving familial care only (n~30);
- older adults with functional limitations not receiving any care (n~30);
- younger and older adults providing care to older adults (n~30);

Constructivist grounded theory will be used to generate and analyse data simultaneously.

*Results:* Fieldwork, incorporating preliminary descriptive results, is planned for July-August 2016. A full paper based on these findings will be ready for submission by September 2016.

## **Long term care policy above the fray? The case of German long term care expansion in the face of austerity**

**Lorraine Frisina-Doetter**

*University of Bremen, Germany*

Co-author: Heinz Rothgang, University of Bremen

*Thematic area:* Institutional dynamics and politics

*Objective:* The establishment of the German long term care (LTC) system in 1994 represents a path breaking event in welfare state development in the post Golden Era. In it, an entirely new branch of social security can be found - one which has since seen expansion in benefits, particularly for those affected by dementia, representing a growing and substantial group of the elderly population. This expansion is at odds with the larger climate of welfare state retrenchment and restructuring experienced in Germany within other policy areas since the 1970s, especially in health care. In an effort to understand these developments, the present study examines the importance of agency and structure in bringing about reform.

*Data and methods:* Primary (e.g. policy and legal documents) and secondary literature are used to provide thick description on historical developments of LTC in Germany, including the rationale and institutional logic surrounding the foundations of the system.

*Results:* Our findings point to the special role of federal institutional structures in influencing fiscal and social policy in Germany; the functional limitations of the health care system which gave rise to the need for a separate system to address LTC coverage; and the political entrepreneurialism of politicians in defining the policy rationale and seizing a window of opportunity for reform.

## **Patient choice of post-acute care provider & hospital accountability**

**Emily Gadbois**

*Brown University, United States*

Co-authors: Denise , Tyler , Brown University, Vincent, Mor, Brown University

*Thematic area:* Case management

*Objective:* Since implementation of the Affordable Care Act, hospitals in the US have become responsible for the care Medicare patients (i.e. those over age 65) receive in the post-acute care setting. Yet, little is known about how those needing post-acute care select a facility or the role hospital discharge planners play in the post-acute care selection process. The purpose of this research was to explore how patients requiring post-acute care make decisions about which nursing home to select and the role that hospital discharge planners play in the selection process.

*Data and methods:* We conducted case studies in eight US cities and interviewed staff (N=160) in hospitals, nursing homes and Medicare managed care organizations (i.e. insurance companies). In five cities, we also interviewed patients (N=97) who had recently been admitted to one of our participating nursing homes. All interviews were summarized immediately upon conclusion. Summaries were used to quantify participants' responses in terms of the number of discharge planners who said they provided patients with quality data, the number who reported providing patients with only a list of facilities, the number of patients who reported receiving quality data, the number who reported using quality data and the number who would have gone elsewhere had their doctor recommended it or if they were told the quality was better.

*Results:* Of the 77 patients who reported being involved in nursing home selection, 57 received only a list of nursing homes. Ten didn't receive lists because they already knew where they wanted to go; in all cases a nursing home where they had previously been. In fact, 35 of the 97 patients reported previous stays at the same nursing home. Only four patients reported receiving nursing home quality data from discharge planners. This is consistent with responses from discharge planners, who reported not furnishing patients with data, but providing only lists of nursing homes. Discharge planners stated they had been told that patient choice statutes precluded them from providing any information beyond nursing home addresses. Because the only 'data' patients were given were addresses, this often resulted in patients simply selecting the nursing home nearest their home and/or returning to a nursing home where they had been. Yet, 73 patients said they would have traveled farther if a better nursing home had been recommended.

*Policy implications:* Patient 'choice' in post-acute care setting is apparently trumping hospital accountability. Further, belief that regulatory requirements regarding patient choice ostensibly precluded discharge planners from sharing quality data about nursing homes means that patients' choices could not possibly be based on quality. US policymakers must clarify what is meant by 'patient choice' and allow hospitals to explicitly refer patients to nursing homes they are willing to vouch for and work with to achieve better outcomes.

## **Patients' experiences transitioning to post-acute care in skilled nursing facilities**

**Emily Gadbois**

*Brown University, United States*

Co-authors: Denise, Tyler, Brown University; Vincent, Mor, Brown University

*Thematic area:* Case management

*Objective:* Among older adults in the US, post-acute care (PAC) is often necessary following a hospital stay. This PAC commonly occurs in skilled nursing facilities (SNFs) and is paid for by Medicare, the government-funded health insurance for those over age 65. Since implementation of the Affordable Care Act, hospitals have become more responsible for the PAC that Medicare patients receive, including financial penalties for

readmissions. The purpose of this research was to understand the experience of patients during the hospital discharge planning and SNF placement process, including the information patients use to make decisions, which factors they view as important in making their selection, and barriers and facilitators to the overall process.

*Data and methods:* We interviewed 97 SNF patients and/or their family members in five cities in the US. We recruited three SNFs within each market (two in the smallest market), and in each facility conducted semi-structured open-ended interviews with approximately seven previously community-dwelling, newly-admitted patients discharged from a hospital. These interviews were recorded, transcribed, and qualitatively coded to identify underlying concepts and themes.

*Results:* Despite different reasons for hospitalization and hospital lengths of stay, most respondents reported that they were required by hospital discharge planners to make decisions regarding SNF placement the day before their hospital discharge. Respondents generally received a list of SNF options which included only the names and addresses of facilities. This list was sometimes limited by location to just a few choices, but many respondents reported receiving a list of every facility in their city (i.e. several pages of facilities). In most cases, hospital staff were minimally involved in the decision-making process, but respondents reported appreciating such help when it was received. Common predictors of patients' decisions included location (not surprising given that the address was often the only information patients were given) and previous experience (either a prior stay or knowing others who had prior stays). Some respondents reported relying on decision-making support from their family and friends; indeed, respondents without involved family seemed to have more difficult and stressful experiences. Most respondents reported being satisfied with their placement, but many stated that they would have been willing to travel farther to a higher quality facility or one recommended by their doctor. Many described the process as overwhelming, stating that they did not know where or how to get help. Despite known differences in how hospitals and SNFs collaborate, patients' experiences in the discharge process were very similar.

*Policy implications:* SNF placement is a stressful transition, occurring at a time when patients are physically vulnerable, and often without significant help or guidance from experienced professionals like hospital discharge planners. Most patients select a facility based on its location, simply because they are provided with no quality information or advice. Hospitals are increasingly responsible for the outcomes experienced by patients post-discharge, yet the discharge planning process remains rushed and chaotic. Hospitals could likely reduce readmissions and other adverse outcomes by helping patients choose better quality facilities most suited to their clinical needs.

## **The unintended consequences of reduced post-acute care lengths of stay**

### **Emily Gadbois**

*Brown University, United States*

Co-authors: John McHugh, Brown University; Renee Shield, Brown University; Ulrika Winblad, Uppsala University; Denise Tyler, Brown University

*Thematic area:* Equity and efficiency

*Objective:* In the US, patients covered by Medicare, the health insurance program for those over age 65, often require post-acute care after a hospitalization. This care is commonly provided in nursing homes. In recent years, Medicare policy changes and market-based pressures have resulted in reductions in median post-acute care length of stay in nursing homes. The purpose of this research was to identify the key challenges that reductions in length of stay pose for nursing homes, the unintended consequences of reduced length of stay for nursing homes and their patients and nursing home responses to these.

*Data and methods:* We conducted case studies in eight US cities and interviewed approximately 20 clinical and administrative staff from hospitals, nursing homes and Medicare managed care organizations in each market, yielding about 160 interviews. This included approximately 70 interviews with administrators,

directors of nursing and admissions coordinators in 25 nursing homes. We used data on risk adjusted nursing home median length of stay for 2012-2014 created for another project to identify the nursing homes with reductions in length of stay and those with no reductions in length of stay. Data from interviews with staff in nursing homes with no reduction in median length of stay were then compared and contrasted with data from interviews with staff in nursing homes with reductions in length of stay.

*Results:* Among the 12 nursing homes where median length of stay dropped, the average reduction in length of stay was 4.0 days. Staff reported several challenges related to reductions in length of stay. They reported not having time to help patients unable to return to the community to find appropriate long-term care and reported having to discharge patients who they felt were unsafe. Some overcame these challenges by developing programs to follow-up with patients post-discharge. While these programs served to ease concerns about patients, they also involved non-reimbursable costs for nursing homes. Some nursing home respondents also noted ways they avoided admitting patients who had the potential to become long-stay. Staff in nursing homes that did not have reductions in length of stay reported not being reimbursed by managed care organizations and other payers for patient stays that had surpassed their pre-determined length. Some also reported patients becoming unexpectedly responsible for the costs of part of their stay.

*Policy implications:* The push for shorter nursing home length of stay has resulted in challenges for nursing homes and possible unintended consequences for patients, including increased costs for care and potentially unsafe discharges. Patients may also have difficulty finding facilities willing to accept them if they may eventually need long-term care. Policymakers should address these issues in ways that ensure patients receive the care they need, are not left responsible for unexpected costs and are not discharged unsafely or to a location that cannot provide the long-term care they may need.

## **The impact of long-term care on primary care doctor consultations for people over 75**

***Katerina Gousia***

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Co-authors: Julien, Forder, PSSRU, University of Kent; Eirini Saloniki University of Leeds

*Thematic area:* Health and social care integration

Many countries are adopting policies to create greater coordination and integration between acute and long-term care services. This policy is predicated on the assumption that these service areas have interdependent outcomes for patients. In this paper we study the interdependencies between the long-term (home care) services and consultations with a primary care doctor, as used by people over 75. Starting with a model of individual's demand for doctor consultations, given supply, we formalize the hypothesis that exogenous increases to home care supply will reduce the number of consultations where these services are technical substitutes. Furthermore, greater coordination of public service planning and use of pooled budgets could lead to better outcomes because planners can account for these externalities. We test our main hypothesis using data from the BHPS for years 1991-2009. To address potential concerns about endogeneity we use a set of instrumental variables for home care motivated by institutional features of the social care system. We find that there is a statistically significant substitution effect between home care and doctor visits, which is robust across a range of specifications. This result has implications for policies that consider increased coordination between health care and social care systems.



## **Variations in care costs of people with social care needs: the impact of telecare**

### **Catherine Henderson**

Country: United Kingdom  
*PSSRU, LSE*

Co-authors: Jose-Luis Fernandez, PSSRU  
Martin Knapp, PSSRU

*Thematic area:* Technology and long-term care

*Background:* Telecare has been advocated for people 'at risk' because of age-related disabilities and in particular for those 'at risk' who live alone (to prevent adverse consequences of falls and other risks to safety). Should we therefore expect that expenditure on people living alone might differ from expenditure on those living with others, because of the presence of telecare?

*Methods:* Data were drawn from a large-scale cluster-randomised controlled trial of telecare in a population with social care needs in England (the 'WSD' study). Variations in the costs of telecare for people living alone and with others over the three months prior to baseline and to 12-month follow-up were explored by fitting multilevel models to the cost data and taking a difference-in-difference approach. The research examined total costs and costs by sector (NHS; hospital services; social care). Two-part models were employed to examine the impact of living arrangements and telecare on hospital and social care costs. Average marginal effects of allocation, time and living arrangement enabled comparison of cost differences between experimental groups over the two time points in those living with others and those living alone.

*Results:* The analyses drew on data from 753 cases (375 intervention and 378 control) with available costs at both baseline and 12-month follow-up. Model estimates and marginal effects of the intervention within subgroups are presented. The policy implications of the results are discussed. Telecare is a complex health and social care intervention; careful interagency coordination is needed to balance expenditure and savings across organisational boundaries.

## **Health care transitions among people with dementia at the end of life**

### **Amy Hsu**

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*Ottawa Hospital Research Institute*

Co-authors: Peter Tanuseputro, Bruyere Research Institute  
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Douglas Manuel, Ottawa Hospital Research Institute

*Thematic area:* Policy implications of dementia

*Objective:* The median survival following the onset of dementia among adults over the age of 65 is 3.3 years; yet, we have a limited understanding of their health care use towards the end of life. The frequency of care transitions in the months leading to death is often considered a measure of care quality, and repeated hospitalizations can have a negative impact on the quality of life for patients with dementia and their caregivers. Information on the health care need and utilization among older adults with dementia is essential to health system planning - in light of our aging population - and will have an important role in clinical discussions at the individual level.

*Data and methods:* Using population-level health administrative data from Ontario, Canada, we examined the health care use among decedents with and without dementia (n = 263,990) in the 12 months prior to death. Our decedent cohort was stratified by the primary care setting at 1 year prior to death - i.e., whether the patient was living in a nursing home or in the community (with and without extended home care).

Outcomes examined include hospitalization days, number of emergency department visits, and total health care cost in the 30, 90 and 360 days prior to death.

**Results:** Nearly 70-percent of decedents with dementia received care in a nursing home in their last year of life, while only 7-percent of those without dementia had been admitted into nursing homes. 21-percent of decedents with dementia in the community received extended home care in their last year of life, and the remaining 11-percent did not receive any extended health care from nursing homes or the home care setting. We observed that care in nursing homes had an impact on the number of hospitalization days; specifically, residents in nursing homes spent between 12.5 and 26.7 fewer days in hospitals, after adjusting for age, sex, rural residence, neighbourhood income quintile, and chronic health conditions. Overall, nursing home residents had comparable health care spending (\$61,556 CAD) as those residing in the community (\$52,236-\$72,323 CAD) in their last year of life.

**Policy implications:** The results of this study suggest that older adults with dementia who live in the community may be at an elevated risk of frequent hospitalizations, especially towards the end of life. Specifically, they will spend two to four more weeks in the hospital than those who received care in a nursing home. Health care planning for older adults with dementia should include a discussion of these risks, and consider the impact of frequent hospitalizations on the patient's quality of life.

## **Improving end-of-life care in the community using the RESPECT on-line prognostication tool**

**Amy Hsu**

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Mathieu Chalifoux, Institute for Clinical and Evaluative Sciences  
Douglas Manuel, Ottawa Hospital Research Institute

**Thematic area:** Personalisation of the care system

**Objective:** Older adults in the community who are frail may receive fragmented and inappropriate care due to poor prognostication, especially when they are nearing the end of life. A principal challenge is the lack of a single tool that can produce results to inform care across a spectrum of needs.

**Data and methods:** The study sample included home care clients in Ontario who received a structured health assessment, using the Resident Assessment Instrument for Home Care (RAI-HC), between January 1, 2007 and January 1, 2014. A predictive model was developed, using Cox proportional hazards regression, to estimate the mortality risk in this population. Using a temporal split sample for model development and validation, our derivation cohort comprised of RAI-HC assessments prior to January 1, 2013 (N = 1,137,976), derived from 436,767 home care recipients (2,434,914 person-years). Our validation cohort consisted of assessments performed between January 1, 2013 and January 1, 2014 (N = 171,602), from 121,636 home care recipients (80,241 person-years). All deaths (N = 244,529) were ascertained through linkage to the provincial vital statistics records from the Office of the Registrar General. The final algorithm will be implemented as an on-line tool ([www.projectbiglife.ca](http://www.projectbiglife.ca)) that can be completed by older adults living in the community, the informal caregivers of older adults, and health care professionals.

**Results:** To assess the value of end of life prognostication tools in community care, we held four focus groups (two patient/caregiver sessions in Ottawa and two home care practitioner sessions in Windsor-Essex County) to evaluate the preliminary version of our online tool, potential metrics for reporting the prognosis, and additional communication information to facilitate the discussion of risks. Preliminary results from consultations and pilot-phase interviews with community care providers suggest that risk stratification instruments play an important role in community care planning. The on-line implementation of this

prognostication algorithm, which has an adaptive design, enables its ease of use by health care providers, the patients, as well as their caregivers. This proves to be a valued feature in knowledge translation and risk communication.

*Policy implications:* As the research is on-going, further evaluation with a larger community focus group will take place in the fall of 2016. Preliminary results suggest on-line implementation of RESPECT presents a valued opportunities for research knowledge translation and patient engagement.

## **Intellectual disability, caring and role reversal**

***Zoe Hughes***

*Care Alliance Ireland, Ireland*

*Thematic area:* Unpaid carers

*Introduction:* For many years, people with intellectual disabilities were the recipients of long term care. Institutions across Great Britain and Ireland housed thousands of individuals who were unable to stay at home for many reasons. It is still the current assumption for many- including policy makers- that people with disabilities are still exclusively in receipt of care, and that that care is being provided by non-disabled family or friends, along with the support of health and social care professionals.

However, many services for people with intellectual disabilities are finding that those in receipt of their services are now in the position of providing care and support to their ageing parents, thanks to a variety of factors which will be outlined in this presentation. This change in circumstance is a cause for concern for those services who may feel ill-prepared to support people with intellectual disabilities in this new role.

Objectives of the presentation:

- 1) Briefly overview the history of intellectual disability and long-term care
- 2) Discuss recently developing demographic, social and policy changes which have an impact on people with intellectual disabilities and their families, including the reciprocal nature and mutuality of care
- 3) Introduce key policy and service challenges regarding people with intellectual disabilities becoming identified Family Carers
- 4) Suggest possible policy changes at national and service level which can address these challenges.

It is likely that this presentation will ask more questions of participants than answer them, and will likely challenge participants to challenge their underlying assumptions and understanding of what intellectual disability means within the world of unpaid care.

With changing demographics highlighting an increasing age profile of people with intellectual disabilities and society in general, and the increased pressure on formalised home care services, understanding the impacts of these on families where there is intellectual disability will be key to ensuring that those who wish to can stay at home for as long as possible.

## **Ageing and elderly care in the Arab region: policy challenges and opportunities**

### **Shereen Hussein**

Country: United Kingdom  
*King's College London*

Co-authors: Mohamed Ismail, Analytical Research Ltd

*Thematic area:* International comparative analysis

Populations are expected to age rapidly in the Arab countries during the coming few decades. However, the current evidence base indicates that many countries in the region are not paying attention to this demographic phenomenon. This is a particular concern as longevity is often accompanied by many years of ill health and disability and most of the countries in the region continue to rely on the family as the primary source of elder care. While the family, and particularly women, are expected to provide increasing support for longer, they are faced by a set of socio-demographic changes that may hinder their ability to provide such care. This presentation focuses on the ageing demographics in the Arab region and reflects on the multiple-roles for women by utilising quantitative analysis of international population and socio-economic indicators as well as reviewing the background literature and current ageing policies in the region. The paper then discusses possible strategies to address increasing long-term care needs through a social capital lens, where support to informal carers particularly women is emphasised.

## **What makes men work in the long term care sector?**

### **Shereen Hussein**

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*Thematic area:* Workforce and migrant workers

Care work with vulnerable adults and older people has been traditionally regarded as women's work. It remains quantitatively and qualitatively characterised by a significant over representation of women. The latter relates, in part, to the evolving nature of care work from the private to the public sphere and the assumed responsibility of emotional care placed on women. The escalating demands on long term care (LTC), due to ageing population and other factors, call for strategies to encourage and enable people with different characteristics to consider employment in the care sector. There is an increasing research interest in men joining and continuing work in this emotional occupation. Some of this research focuses on potential advantages from working in a gender atypical employment, including the presence of some form of a 'glass escalator'. Previous research indicates that for some men who join the sector there are indeed some advantages reflected in higher prevalence in managerial roles and higher average earnings. However, these advantages operate through a hierarchy of other factors. Thus, not all men, particularly those from Black and minority ethnic groups or migrants experience the same 'glass escalator' when working in the gender atypical jobs of LTC. There is a lack of research evidence to understand key motivations for different groups of men to join and continue working in the LTC sector. This paper explores this specific gap in the literature using new empirical data. The latter relates to a unique mixed-methods longitudinal study of LTC workers in England, consisting of a survey (n= 1,342) and in-depth interviews with men (n=21) over two-time periods

(T1: 2010-11 and T2: 2012-13). Analysis of the survey data indicates some significant differences in key motivations of men joining the LTC when compared to that of women as well as inter-gender variations related to personal and workplace characteristics. The qualitative data analysis provides insightful understanding of the decision making process involved when men join the care sector, highlighting the importance of social care policy context and developments, social networks and individuals' overall life projects. The findings are discussed in relation to recruitment strategies and wider policy implications related to LTC workforce development.

## **Shortages of care workers and their training and retaining in Japan**

***Tsuneo Inoue***

*Doshisha University, Japan*

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*Thematic area:* Workforce and migrant workers

*Objective:* Ageing population requires an increasing number of long term care workers. Japan's Ministry of Health, Labor and Welfare estimates Japan needs some seven hundred thousand more care workers by 2025. The current strict budgeting control of Long Term Care Insurance expenditure, however, prevents care service providers from improving working conditions. As a result, care workers are among the lowest-paid workers in the country and the care industry has long been suffering from a high level of turnover. MHLW recently took emergency measures to provide supplemental grants for the sake of wage hikes and the turnover rates of care workers are gradually decreasing. The current turnover rate of 17.7% is still chronically high compared with 15.6% for all industries. Workforce shortages are likely to persist without actions that address the underlying factors causing the shortages, including increase of low-skilled care workers. This presentation thus explores care workforce retention strategies in Japan, mostly focusing on their training and education.

*Data and methods:* The recent trends in supply and training and education of care workforce are analysed based on Care Worker Support Center Foundation's Long-term Care Working-condition Surveys and relevant official reports on training and education of care workers.

Semi-structured interviews were conducted at six care service providers with fifteen care workers to find out employers' retention measures as well as employees' opinions about working conditions, relationship with management, job training opportunities in their organisations and the work itself. The interviews are complemented by a Kyoto Prefecture-wide quantitative survey.

*Results:* The statistical analysis shows well over half of care workers have joined the long term care workforce from other sectors, while care workers fresh from school constitute about ten percent of workforce. This illustrates care service providers have a large number of new employees with insufficient care knowledge and skills.

While relatively large providers interviewed tend to feel no shortages of care workers, other providers report shortages, albeit temporarily. Although all providers interviewed provide induction training, small providers do not assign specific staff for on-the-job training. The prefecture-wide survey looks into assignment of training staff, employees' self-assessment of care skills, intent to continue working and analyse their relationships.

*Policy implications:* Lacking of training and education opportunities for inexperienced care workers may likely to heighten their anxiety and hinder their motivation, possibly resulting in higher turnover. The retention strategies, therefore, should pay more attention to quality of care workforce in terms of training and education. Support measures are essential, especially for small providers, so that they may retain skilled care workers to provide quality care.

## **The discovery of working carers – a new policy challenge in Sweden**

**Lennarth Johansson**

Country: Sweden

*Stockholm Gerontology Research Centre and Aging Research Centre/Karolinska Institute*

Co-authors: Pär Schön, Stockholm Gerontology Research Centre

Maria Ageles Tortosa, University of Valencia

*Thematic area:* Unpaid carers

*Background:* There has been a great scarcity of data on informal caregiving in Sweden. Until recently, population based data on informal caregiving has not been available. This hamper of course, ambitions to describe the informal carers situation and need for support.

*Data and methods:* In 2012 the National Board of Health and Welfare was commissioned by the government to carry out a study of informal caregiving of persons with disabilities and older people, covering the whole country. A national representative sample of 15 000 persons, aged 18 years and older (with no upper age limit) were addressed, with a screening question to identify caregivers; 'Do you regularly help, support or care for someone who needs help with daily chores, personal care or other support due to high age, disability or sickness'.

*Results:* Out of a total response rate of 55 percent (~8 200 persons) some 1 500 persons or 18 percent identify themselves as carers, providing support and care on a regular basis, which corresponds to over 1,3 million persons in the population. Regarding the intensity in caregiving, more than 400 000 persons (6 %) provide help on a daily basis, more than 600 000 (8 %) weekly, and some 300 000 persons (4 %) provide help at least once a month. Approximately 900 000 persons (70 %) of the caregivers were in working ages. Caregiving culminates in the population aged 45 to 64 years, but people over 65 provide more intensive care than younger carers. In the group of carers aged 45 to 64, some 8 per cent (which corresponds to almost 70 000 persons in the population) reported they had reduced working hours due to caregiving duties, and 3 percent (29 000 persons in the population) had left work for the same reasons.

*Policy implications:* The 'discovery' of the working carer, and the work-care issue is a relatively new insight in Sweden. The fact that families are forced to reduce working hours or to leave work due to caring commitments, was not recognized in the political discourse, until the campaign for the national election 2014. Many argued that this development is a consequence of the ageing in place policy and the rapid reduction of LTC institutional beds in Sweden. The fact that some 100 000 persons have quit their jobs or reduced working hours to care for their family members, has shaken the Swedish image of a welfare state with a generous public service, catering for everybody from 'cradle to the grave'. It also threatens the full employment policy and indicate a tougher work life in Sweden in general. Current policy responses on the work – care issue, will be elaborated in the presentation.

## **Housing and services in older age**

**Minna Kaarakainen**

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*Thematic area:* Housing and care

Housing and services for the elderly are going through a major change mainly due to the trend of increasing amount of elderly people living alone in Western countries. There is not enough knowledge of the housing situation and the housing and service preferences among elderly people. Although the elderly want to live in

their own homes, they also want to do that on their own terms with services that support their wellbeing and increase their quality of life. Moreover, financial issues should be considered in a sustainable way. Nevertheless, housing is a major explanatory factor for the health status and the level of care needs of the elderly.

The political aim in the Western countries has been that the elderly should live in their own homes as long as possible and to decrease the amount of institutional care. At the moment, there are various options for the housing of the elderly: from one's own home to institutional care. In Finland, elderly care has been provided by the municipalities but this is going to change since the central government has launched a reform that compels the municipalities to establish regions for health care and social welfare (The healthcare, social welfare and regional government reform package 2016). At the same time, Finnish government has increased the individual freedom of choice in health services that will affect elderly care and housing as well (National Institute of Health and Welfare 2016).

The overall aim of this study is to find out how objective welfare and subjective well-being are met.

The study also aims to analyze the current statuses of welfare and housing and their structure, production and usage. This is done in order to search for and analyze new innovative solutions that enable older people to stay in their homes active and satisfied with their quality of life. The focus of the study is on circumstances in Finland.

During the past years, we have gathered documents and data of Finnish elderly care housing solutions and supporting services from various research projects and proposals considering elderly care services, financing and housing in multidisciplinary angles (health policy and management, social policy, economics, economic geography).

At the moment, we are able to introduce findings from an objective perspective: what sort of housing types, services and funding instruments are provided. Including subjective perspective into this discussion will raise new innovative solutions for the housing of the elderly and the services for them.

This information can be used for developing and benchmarking the housing of the elderly and the services for them even though we know that we need more information and comparative cases from other countries as well. However, we are familiar with European elderly care models and know that there are good practices that could be tested in the Finnish system as well. Based on our findings, we claim that taking individual perspectives into consideration and developing housing and services from these points, sustainable welfare will be increased.

### **Three models for compensating family caregivers**

***Richard Kaplan***

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*Thematic area: Unpaid carers*

*Introduction:* Despite the proliferation of new institutional arrangements for providing long-term care to older adults, most such care continues to be provided informally, usually for no monetary compensation, by members of an elder's extended family. In the United States, for example, estimates of long-term care provided by family members reach 80 percent and in less wealthy countries, this proportion is undoubtedly higher.

Nonetheless, the ethical and religious imperatives that compel such altruistic caregiving face competing concerns as countries increasingly move toward defined contribution retirement plans and away from broadly based social insurance schemes. As only one example, caregivers in such countries cannot use many tax-sheltered retirement saving mechanisms that require receipt of earned income and therefore seriously jeopardize their future financial security.

*Methods:* This paper employs legal and economic analysis of three distinct mechanisms to compensate family caregivers and thereby mitigate the extent of their financial sacrifice. The first mechanism is publicly funded social insurance that pays informal caregivers, including family members. This mechanism is considered in the context of the 2010 U.S. health reform legislation known as the Affordable Care Act, which included a program along these lines.

The second mechanism is tax incentives to encourage families to pay informal caregivers and thereby leverage private resources with public funds in the form of foregone tax revenues. This mechanism is examined in the context of U.S. tax deductions of medical expenses, which include long-term care services.

The final mechanism is legal contracts to pay informal caregivers for the services they provide as employees of the care receiver through ‘family caregiver agreements.’ These contracts are analyzed in terms of their income tax, public benefits eligibility, retirement financing, and intergenerational wealth transmission implications.

*Results:* The long-term care program enacted in 2010 has serious design flaws such as voluntary enrolment, delayed benefit eligibility, and mandatory self-sustainability that exacerbated the potential economic problem of ‘adverse selection’ and caused the federal government to jettison its implementation.

Incentives in current U.S. tax law impose successive statutory hurdles that limit their effectiveness to very few situations. Legislative proposals to address some, but not all, of these limitations have languished and do not appear to have sufficient political appeal to be enacted any time soon, though at least one presidential candidate – Hillary Clinton – has recently resurrected a proposal she first introduced as a U.S. senator.

Family caregiver agreements address the problem of uncompensated caregivers when such agreements are considered with the foresight and comprehensiveness that employment contracts generally require. Nevertheless, such agreements confront serious cultural and tax barriers though they receive significant, if largely underappreciated, support regarding public benefits eligibility.

**Conclusion:** Until a broader consensus emerges in favor of social insurance schemes generally or greater determination to facilitate private payment arrangements via tax incentives, families wanting to address the problem of uncompensated caregivers for older relatives should look at caregiver agreements to achieve ‘second best’ results.

## **Can experiments build a bridge between science, policy and practice?**

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*Thematic area:* Health and social care integration

Finnish government has launched 26 key projects for years 2016-2018. Five of these key projects focus on health and welfare. One of these key projects is named ‘Home care for older people will be developed and informal care enhanced in all age groups’. The total funding for the project is 30 million euros. The Ministry of Social Welfare and Health will coordinate this project that will be executed in cross administrative co-operation.

The expected results of project are to increase equality among older people and their informal carers, to more efficiently coordinate services, and try to cut the increase of health and social care costs in coming years. The program for services for older people has three aims 1) to create an integrated service entity for older people for 18 regions that will be responsible arranging health and social services for their population in the beginning of 2019, 2) to have an experiment on regional level center for guidance of services, a single entry point for all support and services, and 3) to find new innovative ways to provide home care services.



The program for enhancing informal care has both experiments and implementations. In the call, the funded experiments will include models for supporting informal carers 1) of handicapped children, 2) of mental health rehabilitees, and 3) of older people with dementia. In addition, regional level centers will be funded for supporting informal carers with peer coaching, training, health checks, and rehabilitation.

The project has a national level steering group representing various public and private organizations and care providers, a project managerial group, and a council of scientific advisors including ten professors from different disciplines. Main principals of the project include digitalization, evidence based leadership and management, and communication. A full scale transformation program will be implemented.

An open call with specific evidence based criteria for funding will be launched in May, 2016. In beginning of September, the results of the call will be available.

## **Where does the money go? Financialised chains and the crisis in residential care** **Anne Killett and Sukhdev Johal**

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*Thematic area: Funding systems*

This presentation will discuss the public interest implications of the practices of the financialised chains, and the dominant narrative they have developed about a crisis in residential care. In a public interest report we have argued that this narrative oversimplifies the story: the issue is not simply how much money goes into adult care but where the money goes.

In autumn 2015 the large chain care home providers claimed that residential care in the UK was in crisis. The argument was that 60% of care provision is publically funded, and that local authorities were not paying an adequate price for this. They argued that this would lead to the closure of care homes with devastating consequences for people in care homes and for the local authorities responsible for their welfare. This would also have serious implications for hospitals which would rapidly become full of people needing care home provision. However, this is a very partial account of the more complex reasons for the financial difficulty that several chains are experiencing.

We used 'follow the money' research, beginning with an analysis of the history and current business models in the care home sector's large chains. Three of the five largest chains are owned by private equity. In this model financialised providers buy care businesses with small amounts of their own equity and larger amounts of fixed interest debt serviced by the operating business; this leverages returns on equity when profits are made but makes the business more fragile if cash flow falters. This debt based financial engineering approach is also associated with complex group structures that game limited liability so as to avoid tax and allow extraction through internal loans at high rates of interest or sale of assets. While this approach is acceptable in high risk, high return, activities such as commodities and tech company start-ups, it is not appropriate to an activity such as adult social care which is low risk and should be low return. The financial pressure on operations compromises care quality and through the business model reduces the variety in types and design of provision.

We illustrate all these points by analysing in detail the case of Four Seasons which is the largest chain operator of care homes. We also examine the 'fair price of care' model which the trade has used to justify higher prices; and show how it has an 11-12% return on capital embedded in it which, if achieved, would offer care home chains, a risk free return on purchase. Of course, margins have been squeezed by austerity but we argue that the big chain operators should not to be bailed out by the taxpayer for the losses that are the consequences of their own actions. Instead, the state should take the lead in mobilising low-cost finance so that smaller providers (profit and not for profit) can operate new residential care homes and public policy should more generally promote social innovation in the forms of long term care.

## **Barriers to wider use of technology in dementia care and support**

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*Thematic area:* Technology and long-term care

Technologies are not currently widely used in dementia care and support. In this presentation we will consider why that is. A number of barriers will be discussed, including: under-developed technologies; a weak evidence base on those technologies that are now available; the cost of technologies (to different stakeholders); design issues; trust and preferences; limited awareness; the need for individualisation; commissioning limitations; social attitudes to ageing and dementia, linked to technology; and staff skills, awareness and attitudes. The presentation will finish with suggestions as to how to overcome some of these barriers through policy initiatives and practice adjustments.

## **Eligibility and affordability of LTC services – a global view**

**Markus Kraus**

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*Thematic area:* International comparative analysis

*Aim:* The aim of this paper is to identify and assess gaps and deficits in coverage in long-term care (LTC) systems across the globe. This analysis covers a representative group of low, middle and high-income countries in Africa (Algeria, Ghana, Nigeria, South Africa), America (Argentina, Brazil, Chile, Colombia, Mexico), Asia (Australia, China, India, Japan, South Korea, Thailand) and Europe (Germany, Poland, Russian Federation, Turkey, United Kingdom). In the context of the analysis, the national legal background and eligibility for LTC services as well as the affordability of LTC services have been assessed for the respective countries. This analysis helps bridging a gap in literature, as research on LTC system is devoted mostly to high-income countries. Little is known about LTC systems of low and middle income countries.

*Results:* With regard to legislation and entitlement for LTC services in the sample countries, we found that almost two out of three older citizens live in a country where families rather than governments have the legal duty to provide LTC services for older family members who cannot cover their needs on their own. While in several Asian countries the nuclear family is held responsible, in many African countries a more widely

defined family is obligated. Among the sample countries, only a quarter of older citizens can refer to legal rights to LTC services provided or financially supported by the government. As we expected, a legal right to public LTC services is mainly present in high-income countries, while governments of middle-income countries have in general not yet established legal rights to public LTC services. But even in countries with a legal right to public LTC services, this right can be contrasted by a severe lack of capacities to provide the corresponding services.

With regard to affordability of LTC services in the sample countries, we found that information on affordability is only limited and piecemeal, even in high-income countries. We used the presence and levels of out-of-pocket (OOP) payments as well as the share of OOP payments in total LTC expenditure as a proxy for affordability. Among the sample countries, the levels of OOP payments for LTC services are high in African and American countries. The levels of OOP payments vary substantially in the Asian countries. While they are low to moderate in Australia, Japan and South Korea, they are high in India and Thailand. Japan is the country with the lowest OOP payments relative to total LTC expenditures. Even in the European high-income countries, OOP payments are an important source of funding for LTC services. In Germany and the United Kingdom, for example, OOP payments amount to approx. 25% and 30% of total LTC expenditures, respectively.

## **Effects of health checkup attendance on caregivers' physical health**

***Narimasa Kumagai***

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*Thematic area: Unpaid carers*

*Background:* Poor physical health status is more likely in informal caregivers given the roles of living conditions. One of the major problems stemming from the caregiving role was lifestyle change. Caregivers feeling the strain of the role of caregiving responsibility may not participate in health promotion activities to maintain their own health. When looking at caregivers' health outcomes, it may be important the intensity of care provided because caregivers face varying levels of intensity of caregiving stressors.

*Objectives:* Drawing on Grossman's model of healthcare demand, this study explores the determinants of health checkup attendance among informal caregivers in Japan and analyzed the effect of health checkup attendance on caregivers' physical health.

*Data and methods:* Six waves of the Longitudinal Survey of Middle-aged and Elderly Persons (2005–2010) conducted by the Japanese Ministry of Health, Labor and Welfare were used. Taking into account the heterogeneity in the intensity of care provided, I estimated random-effects models of the health checkup functions and physical health functions. Caregivers with regular work were classified as reference category. The Kessler 6 non-specific distress scale was used as mental health measures. Having difficulty in daily life activities was used as physical health measures.

*Results:* This study uncovered three major findings. Firstly, there was not moderate persistence in health checkup attendance of non-working informal caregivers. The effect of initial conditions of most female caregivers were moderate persistent. Second, almost 40% of the probability of health checkups attendance was reduced by co-residential caregiving in females and males. Co-residential caregiving led to the change in health checkup attendance more than non-residential caregiving. Third, health promotion behaviors such as health checkup attendance and exercise habits reduce the risk of poor physical health of inactive female caregivers. In contrast, male caregivers having diabetes or stroke did not attend health checkup and tended to have future poor physical health.

*Policy implications:* Because of the potential negative effects of informal caregiving on caregivers' health, the support of informal caregivers combined with regular health checks is an important public health issue. The estimation results suggested that co-residential inactive female caregivers may benefit from attending health checkups. However, the positive effect of health promotion behaviors on physical health did not exceed the

negative effect of caregiving. Much attention should be paid to lifestyle of non-working informal caregivers. In addition to health checkup attendance, cessation of risky health behaviors such as smoking is strongly recommended.

## **Comparing Japanese and Swedish future LTC cost development 2010 - 2040**

**Marten Lagergren**

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*Thematic area:* International comparative analysis

*Objectives:* Japan and Sweden are similar from many respects with regard to LTC needs and public responsibility to meet these needs. Thus population aging is expected to result in increase of LTC costs in both Japan and Sweden. The study aims to calculate projections of costs of LTC in the period 2010 - 2040 under different assumptions regarding changes in population, needs of LTC by age-group and gender, provided services by level of need and cost of LTC services in Japan and Sweden.

*Data and methods:* Population data were taken from the official national forecasts. The needs projections were based on epidemiological data, the Japanese NUJLSOA and the Swedish SSLC (ULF). Japanese data on LTC services provision by needs and costs for services were taken from nine municipalities collected by assessments in the LTCI-system. Corresponding Swedish data were from surveys in eight Swedish municipalities made for the national tax equalization scheme. The total initial costs were calibrated to agree with official national figures.

*Results:* Two different projections are made for each country - one assuming unchanged dependency by age group and gender, the other assuming that present dependency trend is continued until 2025. For Japan this results in a projected cost increase of 93% and 80% respectively from 2010 to 2040, for Sweden 52% and 24% respectively. The results reflect differences in population aging and health development.

*Policy implications:* The analysis shows that there are substantial demographic and economic challenges facing both countries in the coming decades. The health development by age-group and gender is a crucial factor for the sustainability of the LTC system putting emphasis on the need for successful health promotion and disease prevention. Better decision support is needed to guide policy in this area of the welfare state. This is a task that could benefit from future co-operation between the two countries.

## **Scoping carer research**

**Mary Larkin**

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*Thematic area:* Unpaid carers

There is now a wealth of national and international material and research about carers, However, this body of research is currently fragmented and lacks accessibility and utility, rendering finding information about carer research problematic and impeding its capacity to reliably inform future research. The subject of this paper is a scoping review which will – for the first time – provide a comprehensive overview of existing carer-related research and evidence. This 10 month review, which started in March 2016, aims to scope, capture, organise and synthesise existing national and relevant international carer-related evidence and knowledge. For example, policy and practice documents, research findings/summaries, summaries of carer-related data from national surveys, summaries of events, consultations, websites, reports, grey literature and academic papers/materials.

The methodology adopted focuses on mapping this broad range of research, evidence and knowledge within a framework that enables the material to be managed and structured. Both vertical and horizontal approaches to analysis are being used. Vertical analysis is based on selected characteristics (e.g. age, gender, marital status, ethnicity) of a sub-set of the carer population. The four priority areas of the 2010 Carers Strategy inform the horizontal analysis. These are listed below together with the set of research questions which have been distilled for each priority.

1. Identification and recognition

- a. What is known about approaches to recognising and identifying carers?
- b. How are 'hidden' groups of carers identified and supported?
- c. How are carers recognised and involved in policy and practice development?

2. Realising and Releasing Potential

- a. What is known about the impact of caring on education, training and employment participation?
- b. What support enables carers to remain in or return to education, training or employment?

3. A life outside Caring

- a. What is known about the impact of caring on people's social and leisure activity, family and community participation?
- b. What enables people's participation in life outside caring?

4. Staying Healthy

- a. What is known about the impact of caring on health and wellbeing?
- b. What enables carers to stay healthy?

A matrix that integrates both these dimensions of the analysis and allows cross-reference between different elements has been developed. A template for summarising and categorizing resources in the review was also designed at the beginning of the review and is regularly updated.

In addition to outlining this unique and timely project, this paper will provide a reflection on the methodology and analysis along with some of the interim outcomes and their implications.

## **Costing the impact of informal care on the 50+ in the uk: a standard of living latent variable approach**

***Elizabeth Lemmon***

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Co-authors: Elaine Douglas, University of Stirling  
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*Thematic area: Unpaid carers*

As the population continues to age there is increasing pressure on government and individuals to provide care for the elderly in society. The pressure on individuals to provide informal caring roles for family members is further amplified by recent government legislation aimed at promoting care in the community and the realisation that the elderly would like to live in their own homes for as long as possible. What's more, as the proportion of elderly in our population increases, the number of people living with multi-morbidities also rises, further increasing the demands on family members in their roles as informal carers.

It is therefore becoming increasingly important that the positive and negative impacts of providing informal care are fully understood. This understanding will help policy makers to design policy that adequately supports informal carers in their roles which will in turn ensure that the cared for are well looked after.

This paper builds on the methods used by Morciano, Hanncock and Pudney (2015), and aims to estimate the monetary cost associated with being an informal carer using a novel standard of living (SoL) approach. This approach extends beyond previous methods employed in the literature in that it allows for a more holistic view of the impact of informal caring on SoL and it overcomes many of the difficulties encountered when using traditional costing methods. For example, the SoL approach circumvents the difficulties involved in accurately measuring time spent informal caring, which is an inherent problem in the majority of the costing informal care literature.

Individual and household level data from the 2012/13 Family Resource Survey (FRS) are used. The FRS is an annual survey which collects detailed information on the living situations and incomes of individuals living in households across the UK. The dataset contains detailed information on the provision of informal care as well as questions on material deprivation. For the purpose of this analysis, the dataset has been constructed to contain data on all carers and non-carers aged 50+.

This paper employs a latent variable structural equation model to estimate the monetary compensation which is required for an informal carer to maintain an equivalent SoL to their non-caring counterparts. Several material deprivation indicators are used to construct a continuous index of the unobserved, latent SoL. The structural model estimates the effect of caring, income and other observed individual characteristics on unobserved SoL.

It is hypothesised that informal carers have a lower SoL than non-carers due to the time and resources they have to give up in order to provide informal care. The analysis in this paper will identify the extent to which informal carers' SoL is reduced as a result of providing care. Attaching a monetary value to this reduction in SoL could indicate to policy makers the monetary amount that is needed to fully support an informal carer in their caring role.

## **Person-directed care planning in long term care: a comparative perspective on policy trends and policy-relevant implementation factors**

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*Thematic area:* Personalisation of the care system

Engaging long-term care (LTC) residents in planning their own care is an essential feature of person-centred approaches to LTC. While engagement in care planning has been related to improved quality of care and decreased costs in other care settings, little research addresses policies and practices to effectively engage residents in care-planning in LTC.

*Objectives:* Thus, the objectives of this presentation are to describe how LTC policies address resident engagement in care-planning and to discuss how LTC providers engage residents in care-planning, with reference to policy-relevant barriers, facilitators, and outcomes.

*Data and methods:* Two data sources inform this presentation: (1) an international scoping review focused on policies and strategies for engaging individuals in planning their care across various types of care contexts (642 articles included; 245 retained; 70 assigned primary relevance); and (2) focus groups about resident engagement in care-planning with a diverse group of U.S. nursing home stakeholders (N = 66), including LTC administrators, nurses and nurse aides, clients, and clients' families. The scoping review and focus groups were conducted by an interdisciplinary team who used thematic content analysis to identify prominent themes.

*Results:* Across nations, policies promote LTC resident engagement in care-planning, with emphasis on principles of autonomy, choice, and human rights; policies differ, however, in their specificity and scope (with regards to the level of prescriptiveness and the type of facilities and residents covered). In alignment with policy requirements, LTC providers implement a variety of strategies, such as assessing residents' treatment goals upon admission, integrating residents' preferences into care-plans, posting key care-plan elements in residents' rooms, and implementing bed-side care-plan discussions. Barriers to engaging residents in care-planning include difficulty changing existing processes, limited time for care-planning activities, limited staff awareness regarding the value of and processes for engaging residents, and heterogeneity of LTC populations. Facilitators include leadership support and resident empowerment in the broader organisational culture. Outcomes are consistently found to be favourable, but inconsistently assessed, and include improved resident health and enhanced staff satisfaction. Focus group findings highlighted strategies for operationalising client engagement in culturally and setting-specific ways, highlighting the importance of leadership and relationships.

*Policy implications:* While person-centred care is a consistent policy goal across the body of international research reviewed, meaningfully engaging residents in care-planning requires attention to local factors and processes as well as national guidance. Findings highlight elements of a policy agenda to support LTC resident engagement in care-planning. For example, policies requiring collection of core data elements would support consistent assessment of resident engagement in care-planning and related outcomes. As evidence grows regarding the effectiveness of care-planning strategies, policies can more prescriptively guide providers how to engage residents in care-planning. Furthermore, policies that remove barriers to resident engagement in care-planning may be needed, such as by reimbursing LTC providers for more care-planning time. Ultimately, LTC policy can help translate universal concepts, such as those of choice and human rights, into meaningful care-planning practices resulting in quality outcomes.

## **The relationship between informal and formal care in Denmark and consequences of government policies of curbing formal care**

**Myra Lewinter**

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*Thematic area:* Equity and efficiency

Denmark is internationally known for its relative generous provision of public home care for frail older people. And in terms of the rest of the EU Denmark performs quite well in terms of delivering care, coordinating services and being cost effective. However there has been little attention to the role of informal care in the Danish system and the factors impinging on that care. This is the case all the while the government has been cutting back the formal care system.

This paper wishes to address this issue by first looking at the role that informal and formal care respectively play in elder care. Employment and normative issues influence the division of labor between formal and informal care, especially the preferences of the frail people themselves. In other words formal care supplements and complements informal care, while giving frail people a real choice.

However there has been a steady decrease in public formal care during the past 5-6 years. There is, then, a question of an emerging care gap. If one studies the distribution of disposable incomes for people 74 years

of age and compares it with the decreases in public home care in municipalities, it appears that the greatest cutbacks have occurred in both the richest and poorest municipalities. The paper will discuss some of the consequences of this development.

## **Direct Payments in Residential Care**

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*Thematic area:* Personalisation of the care system

*Objectives and methods:* Local authorities in England are committed to promoting independence and well-being among adults in the local population. Under the Care Act 2014, councils with social services responsibilities must ensure they take into account individuals' personal opinions in relation to their life and their care. One mechanism for promoting such autonomy and control is the use of direct payments, which have been available for people living in the community for many years. Direct payments are defined as monetary payments made to individuals to meet some or all of their eligible care and support needs.

In 2012, the Department of Health decided to accept a recommendation by the Law Commission to extend direct payments to residential care on the grounds of widening equality for people living in nursing and care homes. A small number of local authorities in England have been piloting the programme since 2013. It has become known as 'Direct Payment in Residential Care Trailblazers' because the DH envisaged rolling out the initiative across England from April 2016. The government has now delayed implementation until 2020.

The Policy Innovation Research Unit (PIRU) has been conducting an independent evaluation of the programme since 2013. The objectives of the evaluation are to understand the different ways in which direct payments are delivered to residents of care homes and the challenges surrounding implementation; to assess the impact of the scheme on service users, their families and other stakeholders; and to examine the relative costs and cost-effectiveness of different direct payment models, if possible.

We will report on progress of the trailblazer sites, and the findings from the following methods of data collection: a self-completed survey of service users and family members, a survey of local authorities regarding administration costs, interviews with local authority representatives and providers, interviews with service users, family members, care home managers and social workers, and an online survey of care home providers.

*Findings:* Three 'models' of such mechanisms have been developed in the trailblazers.

These consist of either a full payment covering the whole care home fee; part payment to fund day activities/services; or extra payments direct to the care home, used to fund one-off activities.

The initial findings suggest that the costs and benefits of the programme are variable, depending on the model deployed by the local authority. The model in which a direct payment covers the full care home fee seems easier to set up for councils and care homes, but is less likely to offer service users and family members greater choice of services within the care home.

However, the take-up of direct payments has been far lower than expected, with only around 30 in place when the trailblazer programme formally ended. As a result, the number of completed questionnaires received and interviews conducted with service users and family members with a direct payment have also



remained low. The available evidence suggests that there have been challenges associated with setting up direct payments, and many local authority and care home staff expressed doubts about whether direct payments are the best way to promote choice and control for care home residents. There were also concerns about whether they might adversely affect the financial viability of care homes. However, some providers said that personalising activities could be one of the most beneficial uses for direct payments, particularly for residents with learning and physical disabilities, and most service users who have received direct payments in residential care or their family members were satisfied with them.

## **How men experience the provision of dementia care**

**Klara Lorenz**

*Personal Social Services Research Unit, London School of Economics*

*Thematic area: Dementia and care*

**Objective:** The provision of care to people with dementia poses challenges to unpaid carers. While carers report positive outcomes, such as the feeling of doing something good and right and the positive feeling of taking on responsibility, carers often also experience negative outcomes due to the challenges dementia care poses (Pretorius et al, 2009; Sampson and Clark, 2015). Many carers report that they find that providing dementia care is burdensome and experience mental and physical health problems (Ory et al, 1999; Vitaliano et al, 2003; Pinquart and Soerensen, 2003).

The majority of family care is currently provided by women. However, particularly among older age groups, men play an increasingly important role in the provision of care. According to the UK 2011 census data, a “slightly higher percentage” of retired men than women provide unpaid care in England and Wales (ONS, 2013).

The provision of family dementia care by older men is of growing importance as increasing male longevity enables more couples to grow old together. Male family carers provide an important share of unpaid care while, due to their often high age, they are at risk of being frail themselves. A better understanding of the experience of family male carers providing unpaid dementia care is important to ensure that this group of carers and the people they care for are able to live as well as possible with dementia

**Data and methods:** A literature review using a systematic approach covering PsycInfo, CINAHL and Pubmed has been conducted focusing on the needs, burden, experience and impact of family male carers. The search spans publications from January 2000 to May 2016. Articles included in the review focus on male carers looking after a person with dementia.

In-depth qualitative interviews are being conducted with unpaid carers in England providing dementia care. The interviews focus on the carers understanding of wellbeing which includes discussing positive and challenging aspects of care provision, implications on carers’ physical and emotional health as well as their financial situation. Interviews will be analysed using thematic analysis. For this presentation only male spousal carers will be considered for analysis

**Results and policy implications:** The proportion of men providing unpaid care at older ages has been increasing and is expected to grow. Little is known about the experience of men providing unpaid dementia care. This presentation sheds light on topics such as ‘motivation to care’, ‘approaches to care’, ‘satisfaction derived from care’, ‘carer health’, ‘stress, emotional difficulty & dealing with difficulty’ as well as ‘identity and masculinity’ as identified from the literature review. Further insight on these topic areas will be provided from qualitative in-depth interviews with male unpaid dementia carers in England.

A better understanding of the experience of men providing dementia care is important to inform policies that aim to support carers.

## **Expected longevity and productive ageing involvement among older Chinese in Hong Kong**

**Terry Lum**

Country: Hong Kong  
*University of Hong Kong*

Co-authors: Jennifer Tang, University of Hong Kong  
Gloria Wong, University of Hong Kong  
Mandy Lau, University of Hong Kong

*Thematic area:* Unpaid carers

*Objective:* Participation in productive activities in late-life is known to improve physical and psychological health, as well as an imperative policy objective in ageing societies. Little is known about how and why older adults allocate their time in productive activities among all other roles and activities. This study aimed to examine whether expected longevity, or subjective life expectancy, influenced the decision about participation in productive activities.

*Data:* Participants' expected longevity were assessed using a question asking about the percentage chance that the person will live to be 75 years or more (if currently aged 60-65 years) or the percentage chance that the person will live to be 80, 85, 90, 95, 100, and 105 if their age is 65-69, 70-74, 75-79, 80-84, 85-89, and 90-95, respectively. Productive activities were measured by the total number of hours engaged in employment, volunteering, and caregiving in the past month. Commitment in immediate family role and extended family and social roles were also measured.

*Methods:* This study used a cross-sectional design with quota sampling to ensure adequate number of participants in the age groups of 60-69 years, 70-79 years, and 80 years and older. Participants were recruited from various community elderly centres. Older adults with cognitive impairment (Mini-Mental State Examination cut-off score 18 – 22, depending on the education level) were not eligible to participate.

*Results:* 287 older adults participated in the study. In the past month, they engaged in an average of 2.1 hours in employment, 12.5 hours in volunteering, and 50.6 hours in caregiving. An increase of 10% in a person's expected longevity significantly increased 4.3 hours of engagement in productive activities (95% CI 1.1 to 7.4;  $P = 0.008$ ), after adjusting for age, gender, number of medical conditions, and commitment in other family and social roles.

*Policy implications:* Expected longevity may be an influential factor in determining a person's participation in productive activities. The findings would facilitate our understanding in policies and programmes that target to increase productive engagement of the older population.

## **Long term care system in comparative perspective: private care resources and family involvement in care**

**Matteo Luppi**

Country: Italy  
*Collegio Carlo Alberto*

*Thematic area:* Care models

This work examines the relation between the characteristics of the national Long Term Care (LTC) sectors and the families' involvement in care for older people. A growing literature has employed the notion of defamilization and incorporated the gender dimension into the comparative examination of care model. In relation to the elderly care sector, whereas the gender perspective of caring responsibility has been broadened analysed, and represent an important field of research, the economic involvement of families in the care process and the related economic inequalities have been pursued to a lesser extent. This study tries to fill

the gap by analysing the extent of familialism of the European LTC systems, considering conjointly both the degree of families' involvement in the care process - in terms of time and private financing - and the macro dimensions that determine or affect this degree of involvement. Based on the recent reform processes that have interested the European LTC sectors, we have identified four macro dimensions of LTC systems that may affect the private involvement in the care of older people. The first result of this article, obtained through a cluster analysis, is a division of the European countries considered on the basis of the characteristics of their LTC systems that affect the level of private resources (time and money) that dependent older people and their family members devote to care. The analysis of the grouping of countries through the lens of the families involvement in care process shows the importance played by the identified dimensions in the understanding the balancing of care responsibilities between public and private sphere. The analysis also highlights the absence of a trade-off between the economic and non-economic family care burden: the more time to care is needed, the more out-of-pocket expenditures are required. The study concerns fourteen EU countries selected according to data availability, whereas the main sources of data are represented by two international sources - System of Health account (SHA) and ESSPROS.

## **Checking care workers: international evidence**

***Jill Manthorpe***

*King's College London, United Kingdom*

Co-author: Valerie Lipman, KCL

*Thematic area:* Workforce and migrant workers

*Objective:* This presentation summarises and discusses the findings of a desk-based international review investigating the checking of staff and volunteers working with adults who are vulnerable or at risk (or similarly defined) receiving social care in their own homes, or in day centres or residential care (long-term care facilities). In England, for example, as part of the government's attempts to prevent harm to vulnerable people, employers in the health and social care sectors must check a data base holding personal details of criminal records to ascertain if any applicant or member of their workforce is barred from working with vulnerable adults or if they have a relevant criminal record that might indicate particular risk of harm.

*Data and method:* This review was undertaken in winter 2014/15. It mainly involved a research of internet-based material and databases in the English language. This was further informed by correspondence with experts and practitioners from different countries.

*Results:* The review located multiple practices internationally, ranging from no checks to substantial checks involving fingerprinting. Different national contexts revealed different reasons for carrying out checks. These extended from efforts to stop fraudulent use of government subsidies to minimising the risk of harm to vulnerable adults, and more positively to enhance user and public trust in care providers. A small number of countries place particular emphasis on the rights of individual employees to privacy and rehabilitation and this moral imperative overrides other policy goals.

An extensive range of factors was seen to influence the decisions made by countries on about the different paths they follow. Competing interests have to be balanced between imperatives such as protection and reassurance of the public; balancing the rights of offenders to privacy and rehabilitation with the need for public and vulnerable people's protection; identification of offences that are relevant from those that may not be; provision of effective mechanisms for monitoring and controlling the employment of offenders where there is contact with vulnerable people versus discretion; and the costs of implementing systems and upon whom these should fall.

Several countries were found to have compulsory checks for those working with children, such as Australia, Italy, and New Zealand. Without exception a history of sexual abuse offences against children appear always to be as viewed as potential grounds for exclusion from care work or other forms of contact with children.

Considerations related to vulnerability among adults varied according to locations and personal characteristics.

*Policy implications:* Overall our review highlighted a lack of clarity in publicly available documents about the potentially multiple policy goals of different schemes and suggests that there may be advantages to clarifying the options available from other countries and from seeking high quality evidence about the effectiveness of such checks.

## **Managers' experiences of employing migrant care workers**

**Jill Manthorpe**

*King's College London, United Kingdom*

Co-authors: Jess Harris, KCL; Jo Moriarty, KCL; Martin Stevens, KCL

*Thematic area:* Workforce and migrant workers

*Objective:* Despite free labour movement in the EU, the UK social care sector still relies on migrant care workers and nurses from other parts of the globe. Increasingly rigorous immigration regulations require managers and employers, in the UK care sector as much as other fields of activity such as checking the status of those tenants wishing to rent property, to check and monitor the immigration status of their staff. The aim of this paper is to explore accounts of the recruitment practices and human resources work of care home and home care managers in the social care sector who make decisions about recruitment and employment practices and need to engage in immigration status checks.

*Data and method:* This paper reports secondary analysis of a large data set of interviews with 121 social care managers in England, as part of the (anonymised) study funded by (to be inserted after review). Interviews took place in four contrasting English areas at two time points, over the period 2009-2014. As part of this study we collected information about managers' views and experiences in deciding to employ migrant workers or otherwise, and the work this entailed for them. Interviews took place with care home and home care providers and not care users directly employing their own care workers/personal assistants. Interviews were recorded with permissions and all transcribed and analysed.

*Results:* The data analysis revealed three major themes. Managers' experiences of implementing new and changing regulations revealed a state of vigilance to ensure compliance with the new requirements. Many expressed fears about the risk of being inadvertently found to be in breach of the regulations and about the severity of the penalties. As part of the adaptation to new regulations they described drawing on new sources of recruitment or other pragmatic responses; some however declared that the efforts entailed were sometimes too burdensome.

*Policy implications:* The potentially stressful nature of managers' roles in abiding by the new immigration and employment regulations is revealed in this analysis. Moreover, managers declare that while recruitment remains a problem in social care, their autonomy in recruiting and retaining staff is limited. Policy makers' ambitions to reduce bureaucracy need to be considered alongside the reliance on managers to address immigration permissions as part of their employment obligations.

## **Speaking out for change - a personal story about life in a long term care facility in Alberta, Canada**

**Linda McFarlane**

Country: Canada

*Member of Alberta College of Social Workers*

*Thematic area: Other*

In May 2005 I was discharged from hospital and admitted to a long term care facility in Calgary, Alberta, Canada. I was 57 years old and physically healthy but suffered from depression and akathisia. Akathisia caused me to pace endlessly and I felt trapped in a body that refused to rest. When hospital physicians decided they could do no more and no group homes were available, a long term care facility seemed the only option. The facility I was sent to was owned by a for profit company which had a contract with the government to provide long term care.

My objective is to share my story with you and through telling you my story I hope to deepen your understanding of how vulnerable people in our care systems may feel. It is a unique story but also a universal story as all of us have similar needs for dignity, meaning and purpose, independence and support, choice, respect, quality of life and caring relationships. I hope it will encourage you to continue to listen to residents and their families, improve policies and practices that guide our care systems and advocate for better quality of care and life for those who need long term care.

The data for this presentation are my recall of my years in the care facility, very painful years. Because the care did not meet my needs, each incident where I was treated as less than human is etched in my memory. My method is that of using a narrative - to tell a story that is detailed, honest, and unique.

I will argue that what I endured, including poor care, lack of dignity, choice, privacy, respect, should never have occurred. I dreaded waking up to face each long, meaningless, purposeless and lonely day. Staff did not encourage me to do the things I could do nor did they ask me to help plan my own care. Activities at the facility were more appropriate for children. As I improved, my requests for help to find a more suitable group home were ignored. Through these years, the kindness of some caring staff made life tolerable but staff were often too busy with basic care tasks to spend time with residents.

Fortunately I improved, left the facility in 2008, and have achieved many personal and professional goals. Although my story is unique, reports from family and advocates still say that others suffer from inconsistent or inadequate care. As a result of my experience I have become an advocate for policy change.

Specific policy implications which we can discuss include:

- The impact of government ideology on policy and care (privatization, funding, etc)
- The importance of using research and best practices models to guide policy
- The need for oversight, transparency, advocacy and ongoing quality improvement
- The need to ensure that residents' needs are at the centre of care and that we focus on quality of life as well as quality of care

## **Providing nursing and residential care services in Europe: a greater role for the private sector?**

**Daniel Molinuevo**

Country: Ireland

*European Foundation for the Improvement of Living and Working Conditions*

*Thematic area: Service commissioning and regulation*

The data available shows that in Europe there is a trend towards increasing reliance on the private sector in the provision of residential care services. Using Eurofound's Network of European Correspondents (<http://www.eurofound.europa.eu/network-of-european-correspondents>) our research maps out trends in private provision over the last ten years in all EU 28 Member States. Our aim is to identify the countries and circumstances in which there has been a particular increase in the role of the private sector in residential care, looking at both profit and not-for profit private providers. This includes the identification of relevant policy and legislative initiatives that favor private provision.

Our research also looks at studies analyzing the implications that private provision has for the services delivered. More concretely, we focus on studies analyzing its impact on the quality (covering both medical and non medical aspects) and the accessibility of services in nursing homes and residential care services.

Our research also includes the user perspective by bringing together the main issues of concern for service users organizations regarding the quality of private residential/nursing care services and how it can be improved.

## **Social work effectiveness and burnout: do we need to do more to see if there are links?**

**Jo Moriarty**

Country: United Kingdom

*King's College London*

Co-authors: Jill Manthorpe, King's College London

*Thematic area: Workforce and migrant workers*

*Objective:* There is an extensive literature looking at social work burnout and the links with retention and job satisfaction. Less developed is the emerging literature which explores the effectiveness of social workers in long term care settings. However, the links between the two are rarely considered and the aim of this presentation is to ask why this should be the case and if there are links between the two.

*Data and methods:* The presentation draws on two systematic scoping reviews into the effectiveness of social work with adults and roles and functions of social workers in England to examine what we know about social work effectiveness and burnout.

*Results:* The diverse methodological approaches across different studies mean that the paper will be essentially conceptual, considering what the evidence suggests about ways of developing new empirical research.

*Policy implications:* High rates of turnover among social workers in long term care have mean that government plans aimed at improving outcomes for people using long term care services may be compromised. This paper asks whether more attention to aspects such as job control and autonomy would help improve outcomes for people using services and carers.

## **Quantifying social protection for long-term care in OECD countries**

**Tim Muir**

Organisation: OECD

*Thematic area:* International comparative analysis

It is difficult for people to predict whether and when they will need professional LTC services, but when they do the cost can be high. People struggle to manage large unpredictable costs without insurance – which is why all OECD countries have public LTC systems. However, while the costs of these systems are well-understood (1.7% of GDP on average across all OECD countries) their benefits are harder to pin down. The OECD has been working with the European Commission to change this. Over the last two years, the levels of social protection in 15 OECD and EU countries have been quantified to determine whether the out of pocket costs that people face in different scenarios are affordable or not. This presentation will give an overview of the methodology and findings of this project.

## **Adopting catastrophic public insurance for LTSS: Will the United States follow Australia and England?**

**Pamela Nadash**

Country: United States

*University of Massachusetts, Boston*

Co-authors: Edward Miller, University of Massachusetts Boston

*Thematic area:* International comparative analysis

*Objective:* To review the development of a catastrophic approach to universal coverage for the cost of long-term services and supports (LTSS) in Australia and England—two countries that have enacted (but not yet implemented) legislation adopting this approach -- and examine the history and prospects of catastrophic LTSS insurance in the United States, a country newly considering its adoption, in light of Australia and England's experiences.

*Data and methods:* This is a qualitative study, using document review and key informant interviews.

*Results:* In the US, discussions of the best design for universal coverage for LTSS have considered a wide range of approaches, from the voluntary publicly administered insurance policy proposed under the Obama health care reform, which offered low-value front-end coverage, to high-value comprehensive coverage provided through expansion of the Medicare program, the public health insurance program for the elderly and permanently disabled. A perennial favorite has been catastrophic coverage – a cap on total LTSS spending, which was first considered for inclusion in the 1988 Medicare Catastrophic Care Act – an idea that has recently been revived by the Bipartisan Policy Center, an influential Washington, DC think tank. At the same time, both Australia and England have passed legislation instituting a cap on lifetime LTSS expenses (the 2013 Aged Care Bill and the 2014 Care Act, respectively), although neither program has yet been implemented. England has delayed implementation due to concerns about funding, while implementation in Australia is ongoing. The context of policy adoption differed between those two countries: England, like the US, operates a means-tested safety-net program for LTSS, while Australia offers universal social insurance to cover LTSS costs, albeit insurance with significant user contributions. The English reform also took place very publicly and was much-debated, while the Australian reform has attracted comparatively little public notice. The parallel trajectories of these nations' policy development lends support to social welfare typologies that posit a distinctive Anglo-liberal approach, with a heavy emphasis on means-testing.

*Policy implications:* A caps on lifetime LTSS expenses may be consistent with a means-tested safety-net approach to protecting the public from the potentially high and catastrophic costs of LTSS. This approach may be acceptable in Anglo-liberal states, although the politically important need to protect against moral hazard presents significant challenges for benefit design.

## **The German market for private long-term care insurance: the impact of public subsidies for purchase**

**Pamela Nadash**

Country: United States

*University of Massachusetts, Boston*

Co-author: Matthias von Schwanenflügel, Federal Ministry for Family Affairs, Senior Citizens, Women and Youth, Germany

*Thematic area:* Funding systems

*Objective:* To explore the impact of the German initiative to offer a public subsidy to for the purchase of private supplemental insurance policies protecting against the cost of long term services and supports (LTSS).

*Data and methods:* This qualitative study used review of public and industry documents and data as well as key informant interviews.

*Results:* Germany has one of the largest private long term care insurance (LTCI) markets in the world, with roughly 11 million private policies in force. This presentation discusses its composition and expansion, as well as the role it plays relative to Germany's mandatory program of LTSS coverage, which requires all to participate. However, some receive their mandatory coverage under the public scheme (which serves 89% of the population), while about 9 million are covered privately, through insurance funds that separately provide private health and LTSS insurance coverage. In addition, a commercial market of about 2.4 million in supplemental policies exists, and has been growing, aided by recent legislation. The provision, the 'Pflege-Bahr', provides a modest subsidy for the purchase of certain qualified policies; benefits are modest as well, but overall, the subsidy program allows moderate-income individuals to enhance the benefits received under mandatory coverage, which falls short of meeting the full cost of care. One of the critical design features of the subsidized program is its lack of underwriting; unsubsidized supplemental policies, on the other hand, are able to screen applicants and risk-adjust premiums. Thus, healthy individuals often find that unsubsidized policies offer a better deal, given the small size of the subsidy (a maximum of 5 Euros per month), creating adverse selection for the subsidized policies and providing a significant growth opportunity for the unsubsidized products: indeed, since the program was launched in January 2013, 350,000 subsidized policies have been sold along with 140,000 unsubsidized policies. Over the longer term, this is likely to result in sustainability problems for the subsidized products, raising questions about the rationale for spending public monies on this effort. However, the scheme must be placed in context, as only one component of the reforms that have recently overhauled the German LTCI program.

*Policy implications:* This effort underlines the lesson, taught by the example of recent attempt in the US to introduce a voluntary public insurance for LTSS, that any LTCI product that does not screen participants or risk-adjust premiums must be mandatory in nature, or risk adverse selection and being unsustainable over the longer term. Significant equity issues also arise out of the use of public monies to bolster private insurance markets.

## **Body mass, physical activity and future care use**

**Olena Nizalova**

*University of Kent, UK*

Co-authors: Katerina Gousia, Julien Forder

*Thematic area:* Personalisation of the care system

Previous literature shows that Body Mass Index (obesity status) is a strong predictor of the disability and functional limitations. Relying on the data from the English Longitudinal Study of Ageing over the period from 2002 to 2011, we find that obesity status is also a significant risk factor in determining future informal care



but not formal care use, even after controlling for ADLs and IADLs and for specific existing health conditions, including diabetes, high blood pressure, and CVD. Obese elderly are about 41% more likely to use informal care and privately paid care, but not formal care, in two-year's time. Sensitivity analysis on a restricted sample shows that this result is not driven by prediabetes. The effect seems to be explained by the development of new ADLs/IADLs and functional limitations among obese. We also find that physical activity is associated with a significantly lower likelihood of using any mode of care in the future, with the strongest effect for formal care use, and among males.

## **Do hospital-owned skilled nursing facilities provide better post-acute care quality?**

**Edward Norton**

Country: United States

University of Michigan

Co-authors: Momotazur Rahman, Brown University

David Grabowski, Harvard University

*Thematic area:* Health and social care integration

*Objective:* As hospitals are increasingly held accountable for patients' post-discharge outcomes under new payment models, hospitals may choose to acquire skilled nursing facilities (SNFs) to better manage these outcomes. This raises the question of whether patients discharged to hospital-based SNFs have better outcomes.

*Data and methods:* Answering the research question of the effect of SNF ownership on outcomes and costs is complicated by selection. Clearly, whether a hospital discharges a patient to its' own SNF is not random. Simple comparisons of discharge outcomes across hospital-based and freestanding SNFs, controlling for observable characteristics, will not yield causal estimates of the effect of SNF hospital-based status on discharge outcomes. To address this issue, we instrument for choice of a hospital-based SNF using differential distance from the patient's home to the nearest hospital with and without a SNF. The identifying assumption is that the instrument will be correlated with selection of a hospital with a SNF but independent of patient-specific health issues that would determine selection. With this instrument, we mimic randomization of residents into hospital-based SNFs when estimating the effects of hospital-based status on SNF discharge outcomes. Using national Minimum Data Set assessments linked with Medicare claims, we study a national cohort of residents who were newly admitted to SNFs from a hospital in 2009.

*Results:* After instrumenting for hospital-based status, we found that hospital-based SNF patients spent roughly 5 more days in the community and 6 fewer days in the SNF in the 180 days following their original hospital discharge with no significant effect on mortality or hospital readmission. Medicare spent almost \$2,900 less on a hospital-based SNF patient in the 30 days following their original hospital discharge.

*Policy implications:* Our paper is suggestive of the idea that hospital-based SNFs generate some savings for Medicare over the 6-month hospital discharge period. These savings are largely achieved via lower SNF spending. As health care systems and payers increasingly take on risk for Medicare hospital discharge episodes, these results provide some support for vertical integration of hospitals and SNFs. Clearly, we must be careful in over-interpreting these results. The marginal patient in our model is someone who received treatment in a hospital-based SNF due to their prior residence being differentially closer to a hospital with a SNF. The experience of these individuals may not generalize to the universe of SNF patients. However, at least for these patients at the margin, we do observe some potential savings via lower SNF utilization.

## **Comparing the burdens of two groups of Japanese family caregivers of the elderly: biological daughters vs daughters-in-law**

### ***Seiritsu Ogura***

Country: Japan  
*Hosei University*

*Thematic area:* Unpaid carers

For more than a century, daughters-in-law had been playing the role of the caregivers of the elderly in Japanese families, but, in the last three decades, they have been gradually replaced by spouses and biological daughters. The increased importance of spouses is presumably due to disappearing multi-generation families, but that of biological daughters seem to be more complex. The objective of this study is to identify these reasons, with the help of Caregiver Reaction Assessment, a multi-dimensional psychometric instrument of family caregivers experience. The data we have used is a sub-sample of more than 400 primary caregivers who are either biological daughters and daughters-in-law of the elderly, extracted from more than four thousand national data of caregivers collected in 2011 and 2012. Through our analysis, we have found that the most significant difference in the two groups is the labor market status prior to caregiving, and the magnitude of positive assessment after the caregiving began, while the changes in labor market status of the two groups are similar. It seems reasonable to conclude that more biological daughters quit their jobs to take care of their parents, while more daughters-in-law decline to take care of them because of their jobs.

## **Quantum of public home care provision in Ireland - correlation with economic growth**

### ***Liam O'Sullivan***

*Care Alliance Ireland*

*Thematic area:* Economics of long-term care

*Background:* Ireland has experienced one of the most acute recent economic recessions (2008-2011) in the industrial world. This is being followed by a period of extraordinary economic growth (2014-2016). In parallel with this, over this 8 year period, its population in need of long term care, in particular of home care, has increased by in excess of 25%, using over 65 and over 85 populations as a proxies for estimating home care support needs.

*Objective:* Accurately capture the quantum of publicly funded home care in Ireland over the period 2008-2016

*Data and methods:* A desk based review of primarily (but not exclusively) state health and social care publications has attempted to unravel the complexities of accurately measuring the overall quantum of publicly funded home care supports over this period.

*Results:* The change in the quantum of provision over the 8 years moderately correlates with that of the changes in the size of the economy of the country rather than the needs of its ageing population. A time lag between the reduction in the size of the economy and a reduction in publicly funded home care supports has been accompanied by a delay in the subsequent restoration of pre-recession level provision. Utilisation rates remain approximately 10% lower than historical highs and point to a significant deficit in current care provision.

*Policy implications:* Policy makers at all levels need to make concerted attempts at developing more considered and comprehensive recommended utilisation rates. If, as it seems, that public home care provision mirrors closely economic resources, deferred payment/co-funding models might help weaken such correlation. Finally, we discuss the implications of an ongoing deficit in home care provision in terms of increased pressures on Family Carers.

## **An estimation of the value and the hidden social burden of informal care in Spain**

### **Luz Maria Peña-Longobardo**

Country: Spain

University of Castilla-La Mancha

Co-authors: Juan Oliva-Moreno, University of Castilla-La Mancha

*Thematic area:* Unpaid carers

*Background and objective:* Better living conditions medical innovations and improved health insurance for the population have made life expectancy longer over the last century. However, there is no conclusive evidence on whether elderly people will live longer with good health or, on the contrary, live longer but with considerably worse health. The aim of this study was twofold. Firstly, to arrive at an approximation of the value of non-professional care provided to disabled people living within a household in Spain. Secondly, to analyse the burden borne by informal caregivers in terms of health, professional and social problems.

*Methods:* The Survey on Disabilities, Autonomy and Dependency carried out in 2008 was used to obtain information about disabled individuals and their informal caregivers. The total amount of informal caregiving hours provided by main caregivers in Spain in 2008 was computed. The monetary value of informal care time was obtained using three different approaches: the proxy good method, the opportunity cost method and the contingent valuation method. Additionally, statistical multivariate analyses were performed to analyse the caregivers' burden.

*Results:* Total hours of informal care provided in 2008 were estimated at 4,193 million and the monetary value ranged from 23,064 to 50,158 million euros depending on the method used. The value of informal care was estimated at figures equivalent to 1.73%-4.90% of the Gross Domestic Product for that year. Furthermore, 35% of caregivers admitted to suffering from health-related problems, 62% had social/leisure problems and 48% had work-related problems. The probability of a problem arising was positively associated with the degree of dependency of the person cared for. Thus, those who cared for heavily dependents had a high probability of suffering from any type of problem.

*Policy implications:* Informal care represents a very high social cost regardless of the estimation method considered. A holistic approach to care of dependent people should take into account the role and needs of informal caregivers, promote their social recognition and lead to policies that enhance efficient use of formal and informal resources.

## **The elderly care and domestic services sector during the recent economic crisis.**

### **The case of Italy, Spain and France.**

**Sara Picchi**

Country: Italy

University of Rome Sapienza

*Thematic area:* Workforce and migrant workers

Over the past ten years in Italy, Spain and France, the demographic pressure and the increasing women's participation in labour market have fuelled the expansion of the private provision of domestic and care services. In order to ensure the difficult balance between affordability, quality and job creation, each countries' response has been different. France has developed policies to sustain the demand side introducing instruments such as vouchers and fiscal schemes, since the mid of the 2000s. Massive public funding has contributed to foster a regular market of domestic and care services and France is often presented as a 'best practices' of those policies aimed at encouraging a regular private sector. Conversely in Italy and Spain, the development of a private domestic and care market has been mostly uncontrolled and without a coherent institutional design: the osmosis between a large informal market and the regular private care sector has been ensured on the supply side by migrant workers' regularizations or the introduction of new employment

regulations. The analysis presented in this paper aims to describe the response of these different policies to the challenges imposed by the current economic crisis. In dealing with the retrenchment of public expenditure and the reduced households' purchasing power, Italy, Spain and France are experiencing greater difficulties in ensuring a regular private sector of domestic and care services. In light of that, the paper analyses the recent economic conjuncture presenting some assumptions about the future risk of deeper inequalities rising along with the increase of the process of marketization of domestic and care services in all the countries under analysis. In particular, after a brief description of Iversen and Wren's trilemma, the paper describes: recent state-interventions, since the beginning of the economic crisis, to promote the private employment of workers in the field of domestic and care services; and the performance of the domestic and care sector during the period of economic recession, paying particular attention to the evolution of highly skilled female employment. The analysis carried out in this paper suggests that during the economic recession, the trade-off between wage inequalities, good service quality and the affordability of domestic and care work is likely to be overridden. Public services can represent an overly heavy burden on public finance, while a larger irregular domestic and care private market as well as fiscal policies can contain the (wage) cost of services. All other conditions remaining constant, this would ensure the resilience of the private provision of domestic and care services, as well as the relatively positive female labour market outcomes during the recession. On the other hand, this would also entail a greater wage dispersion in the composition of female employment. In light of that, the paper finally presents some political implications.

## **The impact of elderly care services in-kind on poverty across Italian regions and evidence of the effects of the recent economic crisis**

**Sara Picchi**

Country: Italy

*University of Rome Sapienza*

*Thematic area: Equity and efficiency*

It has been maintained that in-kind LTC services have a significant distributive impact, even discounting regional disparities and low levels of public funding. However, empirical researches on the effects of these type of services in reducing poverty, are still scant. This paper aims to fill the void providing estimates of the antipoverty impact of LTC in-kind services in Italy during the recent economic crisis. This country represents an interesting example for at least two reasons. First, in Italy poverty changes also according to regions or groups of regions. Secondly, it is used as an example because a very fast decentralizing process happened in the mid of 2000s.

There are methodological and normative problems which arise in valuing the monetary value of in-kind public services. The most widely used method is the 'insurance value approach'. The insurance value of coverage to each person is imputed on specific characteristics (such as age, sex) and it is based on the notion that what the government provides is equivalent to funding an insurance policy where the value of the premium is the same for everybody sharing the same characteristics. Based on this approach, the paper presents an analysis of the cross-regional impact of in-kind services on poverty using IT - Silc survey 2007 – 2012. In this study, poverty is analysed using the parametric family of FGT index. According to the value of the parameter, FGT index captures the so called three dimension of poverty: incidence, intensity and inequality.

The results present the difference between the index measured on the equivalised disposable income and the 'extended' LTC income. Two poverty lines have been used in this analysis. The absolute line corresponds to the definition used by the Italian Statistical Institute (ISTAT) while the relative line has been set at 60% of the value of the median equivalent income. In line with the international literature, the imputation of expenditure on public services doesn't result in a significant reduction of poverty at national level. On the other hand, the decomposition by geographical areas indicates large differences between territories. The decrease of FGT index is sharper in the regions located at the lower tail of income distribution such as Southern regions, avoiding them to converge. On the other hand, Northern Regions present reduction of the index closer to European Continental Countries. These territorial differences are mainly based on the level of

per capita LTC expenditure, the elderly people's distribution across income quantile and the consequences of the economic crisis. In particular, the results show a differentiated impact according to the definition of the poverty line. Therefore, the analysis present also an interesting contribution to the methodological debate. The retrenchment of LTC public expenditure in 2010 has resulted in reducing the difference between the index measured on the two definition of income. Finally, the evolution of poverty during the economic crisis of different class of age is also undermining the efficacy of one the most dynamic sector of the Italian welfare state.

## **Reflections on designing a mixed methods research study to evaluate Intensive Home Care Packages for people with dementia in the Republic of Ireland**

**Maria Pierce**

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*Genio*

Co-authors: Fiona Keogh, Genio  
Padraic Fleming, Genio

*Thematic area:* Personalisation of the care system

*Objectives:* A priority area of action of Ireland's National Dementia Strategy (2014) is 'Integrated services – Intensive home support', intended as a way of providing long-term support for people with dementia to remain living well at home and delay admission into residential long-stay care. To address this priority, the HSE is rolling out Intensive Home Care Packages (IHCPs) for 500 people with dementia over three years under the National Dementia Strategy Implementation Programme (NDSIP). A key feature of IHCPs is they are to be tailored to the assessed needs and preferences of the person with dementia and their family members, with the underlying aim of putting the person at the centre of the service. Another key feature is that flexible and innovative approaches should be taken to the delivery of these home supports, but delivered within a standardised framework. Genio has been tasked with designing and undertaking an evaluation of the implementation and impact of the IHCPs to determine the effectiveness of the IHCPs compared to standard care; assess user satisfaction; assess quality of life; and compare costs and cost-effectiveness. This paper describes the evaluation design and offers our reflections on designing an evaluation of a complex and dynamic initiative delivered in real world settings.

*Data and methods:* The evaluation consists of three key elements: an outcomes, process and costs evaluation, incorporating both quantitative and qualitative data. Data comes from a variety of sources. A Framework of Key Performance Indicators (KPI) covering 7 domains was developed to assist in measuring progress with outcomes for the person with dementia, family members and at organisational level and this KPI data will be available to the evaluation. In addition, quantitative and qualitative data collected through an in-depth study of a sample of people with dementia and their family members will inform the outcomes, process and costs evaluation findings. Comparable data will be collected from a comparison group in areas where the IHCPs are not being delivered. Document analysis and interviews with staff and service providers will also be conducted. The study included a group of people with dementia in the design of the evaluation.

*Results:* The evaluation commenced in January 2016 and its design is being finalised at the time of writing (March 2016). This paper will offer our reflections on and learning from designing an evaluation of personalised home care supports for people with dementia and their family members when both the initiative and the context within which it is introduced are complex and dynamic. Emerging findings from the process evaluation will also be presented.

*Policy implications:* IHCPs for people with dementia are a key initiative of the NDSIP and this evaluation will address fundamental questions for policymakers regarding the feasibility of providing long-term care for people with dementia at home, what outcomes are likely for the person and family with this form of care

and what are the associated costs. The detailed process evaluation will also provide practical insights and learning for policymakers regarding the implementation of home-based supports.

## **The end of familialism? Public policy, family organisation and the growth of the home care market in Italy**

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*Thematic area:* Institutional dynamics and politics

The LTC system in Italy is characterised nowadays by a broader universalism in public financing, along with a strong privatisation in service delivery and little attention to care quality. This is the result of a deep change occurred in the last two decades as a consequence of a multiplicity of social and political factors. This paper is aimed at reconstructing the process through which the Italian LTC system has shifted from a traditionally familialistic system to a new system, characterised by a novel combination of familialistic cultural orientation, universalism in public financing and marketization of care delivery.

The paper reconstructs a causal sequence structured in four steps:

1. since the 1990s, the traditional familialistic care model has entered into a deep crisis; this is the result not only of increase in the number of older people with disabilities, but also of the increasing female participation to the labour market. Therefore, not only the ageing of the population but also an increasing difficulty in reconciling paid work and unpaid care, in a context of unchanged family organization, have weakened the traditional intergenerational solidarity on which the familialistic system was historically grounded;
2. the national public welfare system has formally reacted to this crisis with institutional inertia. Given a dual LTC public system based on highly residual in-kind services and a nation-wide cash-for-care programme, more and more dependent older people started requesting cash measures; as a consequence, the Italian public care system has strongly radicalized the cash-based character of LTC provision;
3. the care deficit has been filled up with a dramatic growth in private care provision. This has been largely favoured not only by a loose migration policy tolerating the entry of high numbers of (female) undeclared immigrants, but also by the availability of unconditional public cash transfers. Therefore, the inertia of LTC policy, tied to an automatic increase in the beneficiaries of universalistic cash-based programmes, has driven the dependent population towards a new market-oriented, but partially publicly financed, solution, largely relying on the low-paid care provided by migrant workers directly hired by private households;
4. the growth of this private care market cannot be simply interpreted in terms of a marketization of the Italian care system. The huge reliance on 'family assistants' is to be considered as a reaction of the traditional familialistic system to an increased female employment rate and the subsequent increased re-conciliation difficulties; the inertia of public policy has paradoxically facilitated a solution that makes it possible to adapt the traditional care regime to the new labour market and social conditions.

The paper supports this interpretation by analysing the characteristics and reactions of the public system and illustrating the main social changes causing the crisis of the traditional familialistic model. It goes on to focus on the coping strategies adopted by families, giving specific attention to the growing role of private care providers. Finally, it identifies the central challenges faced by Italian public policy-makers, including the issue of low care quality in the LTC system.

## **The future of social care funding - who pays?**

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With the UK population ageing, deciding upon a satisfactory and sustainable system for the funding of people's long term care (LTC) needs has long been a topic of political debate. Phase 1 of the Care Act 2014 ('the Act') brought in some of the reforms recommended by the Dilnot Commission in 2011. However, the Government announced during 2015 that Phase 2 of 'the Act' such as the introduction of a £72,000 cap on Local Authority care costs and a change in the means testing thresholds would be deferred until 2020. In addition to this delay, the 'freedom and choice' agenda for pensions has come into force. It is therefore timely that the potential market responses to help people pay for their care within the new pensions environment should be considered.

In this paper, we analyse whether the proposed reforms meet the policy intention of protecting people from catastrophic care costs, whilst facilitating individual understanding of their potential care funding requirements. In particular, we review a number of financial products and ascertain the extent to which such products might help individuals to fund the LTC costs for which they would be responsible for meeting. We also produce case studies to demonstrate the complexities of the care funding system. Finally, we review the potential impact on incentives for individuals to save for care costs under the proposed new means testing thresholds and compare these with the current thresholds.

We conclude that:

- Although it is still too early to understand exactly how individuals will respond to the pension's freedom and choice agenda, there are a number of financial products that might complement the new flexibilities and help people make provision for care costs
- The new care funding system is complex making it difficult for people to understand their potential care costs
- The current means testing system causes a disincentive to save. The new means testing thresholds provide a greater level of reward for savers than the existing thresholds and therefore may increase the level of saving for care; however, the new thresholds could still act as a barrier since disincentives still exist.

## **A simulation tool for decision making in long term-care in healthcare systems**

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*Thematic area:* Technology and long-term care

*Objective:* Present a computational support system for decision making in management of chronic patients.

*Methods:* The new system uses a simulation tool based on the Jason multi-agent systems platform to model the chronic care strategy in an entire health department –department 11- in the Valencian Region (Spain). Multi-agent systems allow the tool to include human relationships, preferences and social abilities that take place between chronic patients and healthcare system professionals.

To design the computational system it is necessary to analyze the interactions of patients within the healthcare system (with the possibility of including social resources), based on clinical variables, variables on the use of the system (emergency, previous hospital admissions...) and non-professional support.

The system includes three kinds of agents: patients, healthcare system professionals and a case management team (CMT). Patients are people over 65 years old with one or more of the following conditions: heart failure, COPD, diabetes and hypertension. The patient's personal and medical information will be used by professionals to screen the patient and decide whether she/he is under the CMT or not. Patients not eligible are sent to the conventional healthcare system and, thus, they do not enter the simulated system. When they are selected, though, the CMT acts as the committee in charge of designing a pathway for each of these patients. The system is able to simulate these decisions and successive interactions of patients within the healthcare system.

*Results:* The computational model to be used (i) to refer patients and (ii) to assess the effectiveness of the pathways for specific patients. Examples of indicators that can be geographically represented (in the chosen cartographic unit) are the percentage of patients who require a specific resource (prevent the collapse of services), their age distribution or the total number of referred patients between services. In the pilot the system can simulate a population of up to ten thousand agents in a few seconds (1.13 sec), and a population of fifty thousand agents in around five minutes.

*Policy implications:* The impossibility of testing a LTC model in large scale, and the wide range and complexity of the variables it manages, makes it necessary the use of ICT solutions that can generate virtual scenarios and analyze their repercussions in health and social policy at both local and regional scale. Therefore, the outputs of the simulator will provide policy makers with the long-term effects of different policies on the population considered, as well as on the health system. And, an overall evaluation of the social and economic sustainability of changes in healthcare policies (improving the coordination between health and social system) and effects of these policies on the citizen's quality of life. The system will enable stakeholders to discuss the issue at hand and shape LTC policies to be applied in different welfare contexts.

## **Pay less, consume more? Estimating the price elasticity of demand for home care services of the disabled elderly**

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*Thematic area:* Economics of long-term care

With population ageing, the number of the disabled elderly needing assistance at home to perform the activities of daily living is growing. Home care can be provided either by relatives or by professional services, whose utilization is increasing. Many developed countries implement public programs that subsidize the consumption of professional home care. Despite growing concerns regarding the financing of long-term care, little is known about the price sensitivity of the consumption of these services. The impact of out-of-pocket payments on consumption has been widely studied in the field of medical services; regarding home care services, however, literature has mainly focused on the effect of informal care provision on the demand for professional services. The price sensitivity of home care demand has been little investigated, probably due to data limitations regarding home care producer and out-of-pocket prices.

This paper offers to estimate the price elasticity of the demand for home care of the disabled elderly, by drawing on the features of the French home care subsidy program (Allocation personnalisée d'autonomie, 'APA'). We use a unique dataset collected on purpose from one of the French District Councils in charge of implementing the APA program. It contains original administrative records of out-of-pocket payments and home care consumption of APA beneficiaries. Our empirical strategy exploits inter-individual variations in producer prices to identify the out-of-pocket price elasticity. We first assume prices to be exogenous before



exploring the potential nonrandom producer selection. A censored regression model is used to deal with observational issues.

Our baseline estimations yield a price elasticity estimate around -0.7. This estimate, however, should be seen as an upper bound as we find evidence of endogenous producer selection. To go beyond this issue, we make use of the unequal repartition of home care producers over the territory. We compare the estimates obtained on the subpopulation of individuals residing in municipalities with only one operating producer, to the subpopulation living in better served areas. Overall, our results point to a price elasticity at the intensive margin much lower than unity, around -0.5: a 10% increase in out-of-pocket price is predicted to lower consumption by 5%, or about 45 minutes per month for the median sample consumer. It is comparable to what was found for acute care utilization. We intend to use panel data and additional geographical information on the supply of home care services to check the robustness of our findings.

In terms of public policies, the magnitude of our estimates implies that home care services can be regarded as necessity goods: any increase in price will not be fully compensated by the decrease in consumption. Home care subsidy policies can thus be analyzed primarily in terms of redistribution rather than in terms of allocative efficiency. In addition, our study sheds a new light on unequal access to home care supply depending on territories. It evidences the need for further development on spatial equity in access to home care services.

## **Reablement and shared goals of self-reliance among users and care workers**

***Tine Rostgaard***

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*Thematic area: Institutional dynamics and politics*

According to the European Commission's recent policy initiative on social investment, Danish long-term care for older people offers new and innovative perspectives on ageing and the management of the risks associated therewith. The new policy of 'reablement' (rehabilitating) represents a change from a so-called 'passive' to a more 'active' approach in home care, by offering time-limited, multi-disciplinary, person-centered and goal-oriented interventions. It aims to help frail older people to retain, regain or gain skills so that they can manage everyday living skills as independently as possible. However, little is known about how this affects the cooperation and relationship between user and care staff as well as between care staff of different disciplinary backgrounds. Based on interview and observations in two Danish municipalities, this paper investigates whether the goal of self-reliance is a shared goal and how it is applied in daily practice. Overall findings show that while self-reliance is often the stated administrative goal, it is far from easy to obtain and make attractive to the client, not least in regards to cleaning. The multi-disciplinary approach ensures close cooperation in particular between care workers and physiotherapists, to a degree where the latter sets the standard of good care practice.

## **Social care related quality of life at home and in institutional setting: the case of Denmark**

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*Thematic area: Service commissioning and regulation*

The Adult social care outcomes toolkit (ASCOT) tool has been applied in two major studies of social care related quality of life for older people in Denmark, both as part of national commissions looking into the outcomes of LTC. The paper presents the result on measuring social care related quality of life (SCRQoL) in a home care vs. nursing home setting. The findings are that need for care is obviously higher among residents in nursing homes than among users of home care. In both sectors, users have a significant increase in SCRQoL when receiving care, with a current level of SCRQoL almost at identical levels, but somewhat below the level

for the population at large. Home care users have the lowest current SCRQoL in the dimension of abode and residents in nursing home in the dimension food and drinks. This indicates that regardless of need, social care provisions in Denmark manage to raise the level of quality of life, but the dimensions often identified as key for these users still have some way to go.

## **New entitlement rules for Germany's long-term care insurance**

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*Thematic area:* Institutional dynamics and politics

Entitlement rules are a central issue for all long-term care systems. Right from its start, Germany's Long-term Care Insurance has been criticized for its tight entitlement rules leading to ineffective coverage for people with dementia. In 2006 an expert commission was founded to assess the current system of entitlement. This started a reform process leading to new entitlement rules taking force in 2017. The presentation explains the new system and how it differs from the old one, demonstrates its effects on the number of beneficiaries and their respective claims based on recent studies and discusses why it took more than a decade to pass this reform. Finally, the effects of the reform process on the reform contents are analyzed. Interestingly, the length of the reform process led to a reform that is much more generous than originally expected.

## **Comparative approaches to evaluating the role of long term care in achieving gender equality**

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*Thematic area:* International comparative analysis

This paper is a reflection on the usefulness and desirability of policy transfer arising out of comparative social policy research. It is based on the theoretical and empirical findings of the Fairer Caring Nations project, funded by the UK Economic and Social Research Council as part of the program of work carried out around the Scottish referendum on independence in 2014. The project aimed to draw lessons on how to achieve gender equality using childcare and long-term care policy, and apply those lessons in a national and regional policy context. The research used a systematic Comparative Qualitative Framework to identify six case study countries/regions which scored highly on the Gender Equality Index, and to use policy transfer theories to examine whether it would be possible to construct a 'best policy' scenario that would be applicable in a similar socio-economic welfare state with a lower Gender Equality Index.

Constitutional change (such as increased devolution to Scotland following the referendum) provides a unique 'window of opportunity' to effect policy change. This paper will both present the theoretical and empirical findings of the project, and provide a critical reflection on the opportunities and challenges presented by attempted to achieve applied policy transfer from academic research carried out during turbulent times.

It will be of interest to scholars working in comparative research, gender equality, childcare, long-term care and those interested in national and regional social policy developments; and to those attempting to work in an applied way to engender policy and practice change from academic research.

## **Worker retention in long-term care**

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*Thematic area:* Workforce and migrant workers

This paper discusses the use of three measures of worker retention in the long-term care sector: job contract duration, an extended measure of workers' attachment to employers accounting for temporary layoffs, and the duration of workers' attachment to the Long-term care (LTC) sector. Our findings for Austria illustrate, how joint consideration of these measures can reveal peculiarities of the labour market dynamics in LTC.

*Data and methods:* Applying the Kaplan-Meier estimator to data from the Austrian Social Security Database for the years 1997-2013, we examine duration curves of these three measures for the long term care sector, the overall labour market and benchmark sectors.

*Results:* The results for Austria point to an eminent role of temporary layoffs in LTC. We also find indications for limited crossover capabilities for workers in long term care, keeping them from changing jobs in the sector. These findings emerge from contrasting the three measures with each other. Relying on just a single measure in observing worker retention misses out on such patterns and can thus be misleading when judging the efficient use of labour in LTC.

*Policy implications:* The growing demand for care workers as well as the key role of stable relationships between professional carers and their clients for care quality highlights the importance of worker retention in the long term care sector. To some extent workers exit the sector early on in their careers, which calls for retention strategies opening career perspectives in the sector. The high extent of Job recalls in the LTC sector (unemployment spells ending with a reemployment by the same employer) also deserves policy attention. Job recalls incur cost to unemployment insurance schemes and also lower workers' future pension claims.

## **Competing policies? Experiences from the implementation of an integrated health and social care organization for older people in Sweden**

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*Thematic area:* Health and social care integration

*Background and objective:* Coordination problems are common between authorities and providers of health and social care services for older people. The problems reflects a lack of coordinated care planning and communication between care providers. There are also boundary disputes between the service providers regarding care provision and funding responsibilities. The aim of this study is to describe an integrated health and social care organization for older people in Sweden and how it was implemented and the development and experiences up to date.

*Data and methods:* Both quantitative and qualitative data were collected between 2011 and 2015 in Norrtälje municipality, Sweden. The results are analysed using a theoretical framework based on the concepts of institutional logics and logic multiplicity.

*Results:* The Norrtälje project started in 2006. In 2010 a customer choice system was introduced, which complicated the integration process. Multiple service providers led to an increase in communication problems. Norrtälje took the opportunity to develop their customer choice model in a way that improved cooperation and integrated care services. The results also showed that both the logics of integrated care and customer-choice are manifested in the organisation and provision of home-based care through different goals, principles and practices. The organisation incorporates different components of the logics which ultimately brings possibilities for both compatibility and contradiction. The coexistence of integrated care and customer-choice has resulted in challenges related to user-responsiveness and fragmentation in care provision resulting in lack of continuity and deficiencies in communication.

*Policy implications:* An advantage for the service providers was that they were financed by a joint organization with the municipality being able to coordinate care services without complicated financial negotiations with the county council. We can also conclude that integrated care is the dominant logic, albeit with some tensions, which is evident in the organisational foundation of the home-based care. However, the use of customer-choice has complicated the process of integrated care by advocating provider diversity and the notion of older people as consumers.

## **How do care professionals define ‘good’ quality long-term care? Lessons from an Austrian explorative study**

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*Thematic area:* Workforce and migrant workers

*Background:* The public sector in Europe is under increasing pressure to provide quality long-term care (LTC) for an ever-growing older population, with ever-limited resources at its disposal. One of the areas within LTC that often ends up being squeezed by these interlocking phenomena is the professional workforce. Funded by the Vienna Chamber of Labor, this study investigates the often neglected perspective of care professionals and their perception of how ‘good’ quality care should be defined, and what its achievement entails.

*Objectives:* The primary objective of the study was to explore the perception of ‘good’ care for older people from the point of view of care professionals, using Donabedian’s framework to distinguish between structural, process- and outcome-related dimensions of quality. A secondary objective and the main output of the study was the development of a catalog of main themes and issues involved in the provision of ‘good’ care.

*Methods:* The study employed qualitative methods. These included expert interviews with representatives of the main professional groups working in LTC in Austria, as well as focus groups with mixed groups of care professionals carried out in different regions. The data collection also incorporated a focus group with family carers to explore important overlaps and differences between formal and informal care, as well as interviews with 24-hour migrant carers. The latter constitute a growing ‘grey’ workforce in Austria, a group in many ways caught between the formal and informal sector.

*Results:* The study highlights a number of factors critical to the provision of quality care. First, the continued development of a LTC identity that is distinct from health and social care has important implications for the way in which LTC professionals see themselves, and by extension, for the sector’s public image. A distinct LTC

identity would pave the way for the selection of more appropriate indicators of LTC quality, away from largely medical, clinical indicators and towards a more desirable, holistic conceptualization of user wellbeing. Second, care professionals' working conditions have a strong impact on the provision of quality care. Third, relationships and inter-personal dynamics are central to care work. This includes relationships between care professionals and users, and crucially, between professionals and users' family members and other informal carers, including 24-hour migrant carers. Fourth, the capacity of providers to integrate and coordinate care services depends in large part on how care is structured and financed at the national level.

## **Choosing the best and scrambling for the rest: responses to greater network integration in post-acute care following the Affordable Care Act in the United States**

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*Thematic area:* Institutional dynamics and politics

*Objective:* Following the passage of the Affordable Care Act (ACA) in the US, tighter integration between hospitals and skilled nursing facilities (SNF) and increased managed care presence have created dynamic changes in post-acute care (PAC). We sought to clarify strategies and ramifications from this growing consolidation including how some hospital-preferred SNFs may be able to select specialized patients while other SNFs recruit any and all patients to fill beds. Interview data are used to help elucidate ways these organizations operate and patient access and care may be consequently affected.

*Data and methods:* In a multiple case study approach, we identified 4 hospital markets with a high rate of Medicare managed care penetration and 4 with a low rate in varied regions of the US. We conducted 160 administrator and clinical staff interviews in site visits that each included 2 managed care organizations (MCOs), 2 hospitals and 3-4 SNFs that received either high or low referrals from these hospitals to better understand informant perceptions and experiences in the changing healthcare market. The resulting interviews were subjected to rigorous qualitative analysis to identify themes and trends and compare SNFs with low hospital referral rates to SNFs that received a high rate of hospital referrals.

*Results:* With growing hospital selectivity and tighter integration of hospitals and SNFs, SNFs with high hospital referrals report they are able to specialize and screen hospital patients for post-acute care admission while SNFs not in these favored networks indicate they use marketing techniques in their effort to find sufficient patients. Some of the latter say they must recruit long-term care patients with lower reimbursement who are otherwise less preferred because of behavioral and other issues that make care more difficult. SNFs in preferred hospital-PAC networks report they use nurses to screen patients while SNFs with lower referrals say they use marketing professionals to actively recruit patients. The growing integration of hospitals and SNFs may have the unintended consequence of contributing to unequal access and disparities in care among PAC facilities in the US. SNFs with preferred referrals—the 'haves'—may be able to specialize in recruiting higher paying patients while others—the 'have-nots'—may house long-term care patients with behavioral and complex management issues while receiving lower reimbursement.

*Policy implications:* As preferred SNFs are able to increasingly specialize, attract more lucrative Medicare patients and screen less desirable patients, other SNFs may have to actively attract and accept patients considered more difficult and expensive to treat. Disparities in care may be exacerbated by the increased narrowing of hospital-PAC networks since favored SNFs will be able to cherry pick higher reimbursed patients

while less preferred SNFs are increasingly the sites of care for poorer and more medically complex long-term care patients. If this troubling trend is confirmed with further research, new policies will be necessary to address the widening gaps in access and care.

## **The ideal working situation for residential social workers at intensive care homes** **Masakazu Shirasawa**

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*Thematic area:* Housing and care

The long-term care insurance system in Japan covers at-home medical/nursing care services and nursing care home services. Nursing care homes include intensive care homes accommodating the frail elderly, long-term healthcare facilities for the elderly providing nursing care and training allowing users to live independently at home, and private residential homes for the elderly. The most commonly used facilities are the intensive care homes. There are 8,000 such homes accommodating 520,000 residents, of which nearly 80% have dementia and 70% require intensive nursing care level, and supporting those who cannot live independently at home. Intensive care home employees include care workers, nurses, residential social workers and et.al. Though mocked as 'Jacks of all trades,' residential social workers conduct a variety of tasks. The purposes of this study are to summarize the tasks they perform and their ideal tasks, and to propose what their ideal tasks should be.

Questionnaire surveys were posted to 400 residential social workers on March 2014 and 107 valid responses were obtained. We asked residential social workers about both their ideal tasks and the tasks that they actually carried out. They were asked 41 questions derived from the results of a previous study, and answers were graded on a five-point scale. A factor analysis yielded eight factors for the residential social workers' scope of work: admission support, life consultation related, operation management, care plan making, welfare education center related, everyday life support, assessment, and coordination with external organizations, and for the ideal scope, the analysis yielded the following eight factors: operation management, rights advocacy, admission support, care plan making, welfare education center related, everyday life support, assessment, and coordination with external organizations. The actual vs. idealistic situation for each factor was scored out of five, according to the attributes of the residential social workers. A t-test indicated significant differences ( $p < 0.05$ ) in the following factors: actual and ideal levels were high in 'operation management' as years worked as social workers and age increased; actual and ideal levels were high in 'operation management' and 'care plan making', and the ideal level was high in 'assessment' when the social workers doubled as care managers.

These findings revealed the ideal tasks for residential social workers were to support admission, design care plans based on assessments, provide support in daily life and protect residents' rights, operation management, welfare education, and collaboration with other organizations, though in reality, the assessment tasks were unclear even when the social workers had been involved in making care plans, as was the protection of residents' rights. Meanwhile, a variety of categories exist in the current 'life consultation related tasks', creating their image of 'Jacks of all trades'. It also clarifies that doubling as care manager facilitates the work in the social work area of tasks, since the assessments and making of care plans for residences are cited as their ideal tasks. And the more the facility required experience or age, the more the levels increased in operation management; it is necessary to investigate if this task requires experience or if young, capable, social workers can perform it. The quality of life of residents at intensive care homes will be improved by clearly defining residential social workers' tasks and by cultivating human resources according to the relevant needs.

## Evaluating purchaser performance in promoting quality through budget reallocations

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*Thematic area:* Economics of long-term care

*Objective:* It is unclear whether single payer systems outperform multiple payer systems in terms of value-for-money. Single payers may hold more leverage over providers, whereas multiple payers have stronger incentives due to competition on the purchaser side. One means for purchasers to increase value-for-money is to reallocate resources from low-performing to high performing providers. Purchasers may also reallocate budgets based on patient needs. The dynamics resulting from such reallocations can be seen as an indicator for purchaser performance. In the Netherlands, single and multiple payer purchasers appear alongside each other, enabling a comparison. The Dutch have 9 competing insurers purchasing primary and hospital care (multiple payers), and 32 non-competing regional care offices purchasing long-term care (single-payers). Our aim is to research how each purchasing system performs in terms of budget reallocations.

*Data and methods:* We construct a theoretical budget reallocation model based on purchasers aiming to maximize patient welfare under a principal agent relationship. In our model, budget reallocations increase bankruptcies and adversely affect continuity of care. As a result, reallocation outcomes depend on changes in patient needs, differences in provider quality and the relation between reallocations and continuity of care. Purchasers aim to increase market dynamics until loss of continuity of care through bankruptcies outweigh the positive effects of improved needs adherence and provider quality. In order to test the relative effect of these factors on market dynamics, we empirically estimate a linear fixed effects panel model.

To this aim, we collect annual provider financial statement data of all Dutch health providers, demographic data from the Dutch Statistical Bureau and publicly available quality data from the Dutch Quality Institute for the years 2007 to 2014. Correcting for mergers we track budget allocations over time. Next, we calculate the share of the total budget reallocated between providers over time in different purchaser systems. We document changes in national policy to isolate the effect of purchasing on market dynamics. Payer system comparisons may be biased as short term hospital care enables faster budgetary changes compared to long term care. To reduce bias, we distinguish long term trends in reallocation from short term fluctuations. Using market dynamics as dependent variable, we estimate the fixed effects model. We use purchaser characteristics, provider quality, patient needs and bankruptcy rate as independent variables. To check for robustness, we use different combinations of control variables.

*Results:* Current results are preliminary. Single payers reallocate about 3% of total long-term care resources between providers annually, while multi-payers reallocate about 4% for hospital care.

*Policy implications:* Governments have been aiming to improve purchasing, both in multiple payer systems as in single payer systems. The role of purchaser budget reallocations as a means of stimulating value-for-money is often overlooked. Further insights into effects of purchasing on market dynamics allow policy makers to promote purchaser efforts in obtaining high value care.

# **The economic consequences for households of copayments in long term care.**

## **Evidence from Spain after the 2012 reform**

### ***Isabel Pardo-García***

*University of Castilla-La Mancha, Spain*

Co-authors: Francisco Escribano-Sotos, University of Castilla-La Mancha

Raúl Del Pozo Rubio, University of Castilla-La Mancha

*Thematic area:* Equity and efficiency

*Objective:* The objective of this paper is to estimate the contribution of users to the financing of long term care after the passing of the 2012 Dependence Law and to analyze the economic consequences that this modification has had on Spanish households in terms of impoverishment and catastrophism.

*Data and methods:* The data base which was used is the 2008 Disabilities, Personal Autonomy and Dependency Situations Survey since it provides information on the types and degrees of disability, impairments and limitations as well as information on income and the tax revenues of people with disabilities.

First, people with disabilities were classified according to the different types and degrees of dependency defined by the Dependence Law (DL) and according to the level of support required to carry out basic personal and instrumental activities of daily living which are considered in the rating scale of the DL.

The copayment was estimated from the income of dependents and the distribution of social benefits which were made according to each type and degree and regional community. The calculation of the copayment for each type of payment was made in line with its legislative definition.

To analyze whether the copayment had contributed to the impoverishment of households, the methodology proposed by Wagstaff and Van Doorslaer (2003) was followed and poor households were compared before and after copayment. At the same time the extent to which copayment had led to catastrophism was analyzed using different thresholds.

*Results:* The results show that following the 2012 reform, the contribution of dependent people to the financing of the services they receive exceeds by 50% the costs of these services. In terms of revenue, this contribution entails a third of their revenue for moderate dependency (Grade I) 32.35%, almost a half for severe dependency (Grade II) 45.38%, and almost two thirds for major dependency (Grade III) 65.89%.

This expenditure entails an increase in the number of households that live below the poverty line by 17.86% for Grade I, by 21.10% for Grade II and by 24.40% for Grade III. The average monthly poverty gap for new poor households as a consequence of copayment ascends to 326.9€; while households which were already poor, have seen this gap increased by an average of 444.20€.

In terms of catastrophism, more than 80% of households dedicate more than 10% of their income to dependency copayments. Households which dedicate more than 40% of their income to financing dependency on care allowances represent 29.77%, 56.00% and 71.39% for Grades I, II and III, respectively.

*Policy implications:* The 2012 reform has increased the financial commitment of Spanish households to financing long term care. This distribution is unequal according to degrees of dependence, where Grade III is the one which has increased the most. In this sense, the authorities should think about the reduction of copayment for the poorest households and/or according to degrees, since demand is more inelastic the greater the level of dependency is.



## **Individual saving behaviour and the welfare consequences of alternative means-testing policies**

**Pei Sun**

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*Thematic area:* Economics of long-term care

The process of population ageing is dramatically increasing the demand for long-term care. The potential cost of providing care has become a major concern for both governments and households. Many individuals still view themselves as under-insured. From the public perspective, the underlying economic question is how adequate real resources can be redistributed to support long-term care needs and how accurate is the targeting of policy. The paper addresses this question by testing the welfare effects of different means-testing policies (varying from threshold and subsidy level) on different groups of individuals across the income and health level distributions. We do this by using a life-cycle model with after-retirement health shocks that has personal savings or government subsidies as the funding methods for long-term care. The paper gives a thorough analysis of how individuals' saving behaviour changes when facing different government subsidies and means-testing thresholds. Alternative means-testing policies for long-term care, one with a top-up choice and one without, are simulated to evaluate welfare under these two funding regimes. The results show that the means-testing regime with a top-up option generates higher social welfare. Under a means-testing regime with no top-up choice, when the government increases allowance more individuals will choose to decrease their savings on purpose to stay under the threshold, which causes social welfare to decrease. When government issues a policy to cover individuals' long-term care under a constant budget, the government should increase the level of the subsidy and lower that of the government threshold to achieve higher social welfare level.

## **Partner care: On the way to gender equality in Spain and Sweden**

**Gerdt Sundström**

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*Thematic area:* Unpaid carers

*Objective:* In many countries marriages last longer and older persons increasingly live just with their partner, rather than in extended households. Among married/partnered older persons living just as a couple is now the most common household type in Spain and prevailing altogether for older Swedes. We study the consequences for caregiving among older men and women in culturally distinct Spain and Sweden.

*Data and methods:* We use secondary analysis of large national surveys.

*Results:* Equally many older men and women in couple only households provide care for their partner in both Spain and Sweden, and men and women seem to provide equal 'volumes' of care, assessed as hours of caregiving. Our estimates also suggest that a large fraction of all informal care – outsizing public care – is provided by older persons. Patterns of caregiving change in 'familistic' Spain, challenging stereotypes about 'typical' carers being primarily young and female. Swedish carers are older and well on the way to gender equality.

*Implications for policy:* Support programs may have to consider the specific needs of partner carers who are often old themselves, although for many carers the best support are good 'ordinary' services, for the person they care for.

## **Socioeconomic status and engagement in work, volunteering, and caregiving activities among Chinese older adults in Hong Kong**

**Jennifer Tang**

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University of Hong Kong

Co-authors: Terry Lum, University of Hong Kong  
Gloria Wong, University of Hong Kong  
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*Thematic area:* Unpaid carers

*Objective:* This present study aimed to compare the patterns and levels of engagement in productive activities between older adults with different levels of socioeconomic status.

*Data:* Participants' socioeconomic status was inferred by their housing (public rental or private) and personal income. Productive activities were measured by the types and total number of hours engaged in employment, volunteering, and caregiving activities in the past month.

*Methods:* This study used a cross-sectional design with quota sampling to ensure adequate number of participants in the age groups of 60-69 years, 70-79 years, and 80 years and older. 310 participants were recruited from various community elderly centres and participated in face-to-face interviews

*Results:* Participants living in public housing engaged in an average of 47.8 hours of productive activities in the past month, in contrast with 70.6 hours of productive activities performed by participants living in private housing. Participants with higher income were more actively engaged in all types of productive activities. The effect of income on work and volunteering activities remained significant after adjusting for age, gender, education level, marital status, and health condition.

*Policy implications:* Older adults with higher socioeconomic status were more actively involved in productive activities, especially in work and volunteering. Further exploration is needed to investigate whether under-participation may be due to the lack of information or knowledge about the activity opportunities.

## **Being dependent rather than handicapped in France: does the institutional barrier at age 60 affect care arrangements?**

**Marianne Tenand**

Country: France  
Paris School of Economics & Ecole normale supérieure

*Thematic area:* Equity and efficiency

In developed countries, individuals having difficulties to perform the activities of daily living may benefit from public home care subsidies. Such subsidies may cover part of the cost of professional home care services or, in some cases, be used to compensate informal caregivers. One notable and distinctive feature of French long-term care public policies is that they distinguish between handicap schemes, accessible to individuals below age 60, and dependence schemes, open to those aged 60 or more. Public debate has been going on around this 'age 60 barrier', some voices raising the concern that it could induce unfair compensation of the expenditure costs of disability. However, handicap and dependence schemes differ in many ways – eligibility conditions, type of care that can be subsidized, copayment rates -, making it difficult to compare them. We offer to exploit individual survey data and econometric techniques to assess whether this institutional

threshold has an impact on non-medical home care utilization rates among the community-dwelling disabled population.

We use the French Health and Disability Survey on Households (HSM) to get a sample of individuals aged 50 to 74 with restrictions in at least one IADL or ADL. We use a Regression Discontinuity Design (RDD), considering the age 60 as being the threshold besides which dependence schemes become accessible. We fit a bivariate probit model to account for the simultaneity of formal and informal home care utilization decisions. We also control for a large set of individual and family characteristics that could affect home care utilization independently from the difference in public schemes available.

We find that, conditional on living in the community, being a 'dependent elderly' rather than a 'handicapped adult' increases the probability to use non-medical professional home care by 6 to 10 percentage points. This effect is large given that only 7% of individuals aged 50 to 59 receive formal home care. The decrease of informal care utilization around the threshold is of smaller magnitude (2 to 4 percentage points) and less robust, but is suggestive of small substitution effects, consistent with what is found in the literature. However, the probability to receive any home care does not appear to be affected.

Using the same RDD strategy and a complementary dataset on the population living in institution, we also find evidence that the institutional threshold of age 60 affect living arrangements. The probability to live in institution rather than in the community increases by around 3 percentage points at age 60.

Overall, these results show that the institutional barrier at age 60 has substantial impacts on the way individuals' restrictions in the activities of daily living are being compensated. This is new evidence that care arrangements do respond to long-term care public schemes. Our results also contribute to the growing literature that documents the importance of the design of long-term care policies on care utilization. Finally, our paper has important implications for French home care policies, as the right to equal disability compensation irrespective of age does not seem to be guaranteed.

## **An analytic approach to service needs assessment in elderly care**

***Merja Tepponen***

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*Thematic area:* Case management

The objective of this paper is to introduce a Clinical Decision Support System (CDSS) for the service needs assessment process in elderly care. The CDSS was developed in the South Karelia District of Social and Health Care (Eksote) in Finland. Eksote is a forerunner in the development of health and social care services in Finland, and improving process efficiency through creation and utilization of CDSS has been one of the focus areas during the past few years.

The purpose of the service needs assessment process is to analyze and determine a person's needs for care and various services. The service needs assessment process ensures that a person receives the right care and service in a timely manner. Service needs assessment is done as the first step in every contact between a patient/customer and an Eksote representative.

The focus of this paper is on the service needs assessment process in elderly care. The primary objective in elderly care is to allow the elderly persons live in their homes as long as possible. Thus, the service needs assessment process is needed to determine the level of home care services needed. If an elderly person

cannot stay at home even with home care services, the right type of care in a nursing home or hospital needs to be defined.

The general objectives Eksote have set for the development and utilization of CDSS solutions are effective workflow management and standardization of tools. In the service needs assessment process in elderly care, the developed CDSS ensures that the assessment is done holistically and based on equal criteria and tools for each person. Furthermore, the CDSS supports in the management of the ever-increasing number of potential customers in elderly care.

The developed CDSS has been in use for about a year by now. In the paper, we present results and experiences from actual usage by using both quantitative and qualitative measures. The overall perception of the CDSS is positive as it has helped in ensuring that the elderly persons receive the right services.

## **Carers with migrant background and the professional care infrastructure in Germany: patterns of integration and the interaction of policy fields**

**Hildegard Theobald**

*University of Vechta, Germany*

*Thematic area: Workforce and migrant workers*

*Objectives and background:* Since the 1980s, in many western countries long-term care policies were considerably reformed either by the establishment of new, universally-oriented policies, such as e.g. in continental European countries and/or by an often market-oriented restructuring of the professional care infrastructure. The policy reforms significantly impacted on the situation of the care workforce – characterized by an expansion of care employment, efforts to qualify care workers but also often by a worsening of the employment- and work situation. In many western countries, the rising demand for professional care workers and the difficult employment- and working conditions in the field resulted in an increasing employment of carers with migrant background. More recent research revealed that the patterns of integration of professional carers with migrant background in the care infrastructure show a clearly country-specific image. In the focus of the paper is the analysis of the situation of professional care workers with migrant background in Germany. It proceeds by the assumption that the patterns of integration of care workers with migrant background in the professional care infrastructure are strongly influenced by an interaction of long-term care policies, employment regulations and professionalization approaches and migration policies. Thus, the paper aims to reveal the patterns of integration of professional carers with migrant background in Germany and explain them by an analysis of the interaction of the policy fields.

*Conceptual background, data and methods:* Theoretically, the paper is based on an own conceptual framework combining neo-institutionalist approaches created within international comparative research on welfare-respectively care policies for an analysis of the relevant social policies and the definition of the interrelationship between policy approaches and the situation of professional care workers. Empirically, it is based, first, on an examination of the policy design in long-term care policies, employment- and professionalization policies as well as migration policies in Germany. Second, for the analysis of the employment- and work situation of care workers with migrant background – the main empirical part - it draws on findings of a representative research project in Germany based on a questionnaire with approx. 650 professional care workers in home-based - and residential care provision conducted under the direction of the author. The data are analyzed based on statistical procedures.

*Results and policy implications:* The results show differences but also commonalities in the patterns of integration of professional carers with respectively without migrant background, such as e.g. working-time arrangements, caring tasks, training levels etc.. However, the basic patterns are strongly mediated by the training levels of the professional carers. The findings can be explained by an interaction of the effects of the policy approaches, such as e.g. the country-specific expansion of professional care work defined by long-term

care policies, the professionalization approaches; i.e. occupational training programs and regulations of care work and the citizenship status of the care workers.

## **The other way around? New perspectives on LTC policies in old age care in Sweden and Spain**

***María Ángeles Tortosa***

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*Thematic area:* International comparative analysis

*Objective:* The traditional perspective of analysing LTC policies often leads to a 'catastrophic' scenario of future old age care, and also the work-care balance for caregivers. This perspective put a lot of emphasis on purely demographic factors and employs a top-down approach. In medium-long term future most countries will need a huge amount of personal and financial resources for taking care of older people. This is a part of the ageing 'future threats'. Therefore, there are good reasons to question this traditional perspective.

The main aim of this study is to compare the traditional top-down perspective of analysis with a more bottom-up oriented perspective, which focus less on demographic factors, instead more on the role of family members (younger or older) and their work situations.

*Data & methods:* Sweden and Spain, which are both facing the challenges of an ageing society, were selected due to their different cultural, economic, family and labour market conditions, as they represent different points of departure: the Swedish welfare state model versus the Spanish family-based model. We use different macro and micro data for last decades from both countries about demographic, older care caregivers' situation, family life and work conditions.

*Results:* Changing perspective of analysis from a top-down to bottom-up we pass from a 'dramatic' future scenario on old age care to a less pessimistic one with more clear options for action to help caregivers and older people in both countries.

*Policy implications:* A top-down oriented perspective leads to same type of problems in Sweden and Spain: enormous needs of persons and financial resources. That seems to imply same kind of solutions for both countries, policies more close reform paid care and in kind services, that is without considering the role of family transfers and older people as worker or caregivers.

Thinking the other way around, using bottom-up perspective provides new insights on families and older people needs and resources, and takes family as a central point for future developments of old age care policies. Sweden and Spain will have to apply both perspectives of analysis for better design of their LTC policies.

## **Regional variability in long-term care services in Spain: needs, service use and diversification**

**Maria Angeles Tortosa**

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*Thematic area:* Local vs. central policy interactions

*Objective:* Ultimately there is international interest in the study of equity distribution of services for older people. There are different types of approaching this. Most common analysis done focus on comparisons among countries and employing information related with public expenses and on income of people. In this study we want to analyse regional equity in these services for Spain and its regions, but according to needs. The aim of our study is to explore how social services for older people respond to their individual needs, in different regional models defined by the level of service coverage and diversification.

*Data and methods:* We have used individual interviews from 2008 EDAD (N = 45,553) survey and the regional statistics from IMSERSO (2008, 2010), population records from 2008 and census data for 2011 (INE 2011). We classify the Spanish regions by total public service coverage and the degree of diversification of their services. Thereafter, we estimate multinomial regressions considering these micro and macro data to explain the behaviour on use of services by users depending on group of regions, and later separately by gender.

*Results:* It appears great services variations among regions. And we obtain 4 groups of regions according to coverage and diversification services rate. Most regions are in an intermedium and lower situation among coverage and diversification. Regressions estimations tell us Spanish regions with more diversified services seem to target needs somewhat better, that is, to have fewer older persons with unsatisfied needs and also distribute number of services more accurately to their physical frailty conditions. Furthermore, men and women profile use were scarcely different.

*Policy implications:* There are substantial regional variations and inequities in Spanish services for older people. Regions target services primarily to, and best, for persons with the greatest physical needs. Diversification of services 'pays off' but services also should address social vulnerability.

## **Quality improvement over and above minimum standards: a study of providers of residential care for older people in England and Australia**

**Lisa Trigg**

Country: United Kingdom

*London School of Economics and Political Science*

*Thematic area:* Service commissioning and regulation

Governments have experimented with different policy instruments to influence quality among providers of care for older people. There has been a trend towards the marketisation of care and policies with an expectation that this in itself will improve quality. At the same time, marketisation has also been accompanied by a significant increase in government interventions and activity to influence quality and efficiency from a distance. All of this activity is based on the assumption that government intervention can play a part in encouraging providers to both meet, and go above and beyond, minimum standards of quality. Studies in other sectors, principally concerned with environmental regulation, have found that, while regulation and other government actions play a part, alternative explanations for external influence on provider behaviour include economic pressures, political and social pressures and characteristics related to management and attitudes [1, 2].

This presentation will focus on residential care for older people, and reports from a study exploring what part external factors play in influencing the efforts of providers to improve quality 'beyond compliance', and what part do government activities and regulatory actions play. Semi-structured interviews were carried out with managers and other staff from a group of ten for-profit and not-for-profit providers and other stakeholders, drawn from a single local authority in England and a single planning region in Australia. The providers sampled were identified as being 'high quality' providers – a process which proved to be challenging as the definition of quality and the use of inspection ratings is different in England and Australia. The challenges of this process will be highlighted in the presentation. The presentation is part of a larger study comparing the regulatory systems in place in England and Australia and will highlight the similarities and differences between the two countries, as well as the differences between different types of providers.

1. Kagan, R.A., D. Thornton, and N. Gunningham, Explaining corporate environmental performance: How does regulation matter? *Law & Society Review*, 2003. 37(1): p. 51-90.
2. Thornton, D., R.A. Kagan, and N. Gunningham, When Social Norms and Pressures Are Not Enough: Environmental Performance in the Trucking Industry. *Law & Society Review*, 2009. 43(2): p. 405-435.

## **Social care governance structures and the business model at early stages of integrated care design and development in a LMIC region to create cashable savings and RoI**

***Stella I. Tsartsara***

Country: Belgium

*South East Europe Healthcare*

*Thematic area: LTC in LMIC countries*

*Introduction:* Chronicity is the first cause of healthcare cost burden and will continue to increase due to the growing longevity worldwide. National and local care budgets are already experiencing severe cuts not only in EU countries under crisis (Greece, Karanikolos et al) but also in advanced economies such as the UK (NHS recent social care cuts, *The Guardian Social Care* 2016). A solution must be found imminently that it is not dependent neither on state funding that is in constant decline in social care which is the primary driver of Chronic Care nor on Private Equity managing LTC, a high risk option that has failed dramatically over the last years to assure community based care (Four Seasons closing residential care in UK, *The Guardian Social Care*, 2016). The burden in finding a solution is transferred to the local communities that either are offered slim resources such as the increase in local tax for social care of 2% in the UK or not at all as in Greece. The national and local authorities are defensive in moving forward with care reforms as those demand serious investment from state resources. None of the care reform proposals actually proposes how to generate income to build a sustainable community based system for long term care especially.

In this research we are proposing a community based integrated care model that is established on local resources that are lateral to the care services provided to the local population such as for instance senior tourism, health tourism and thermal rehabilitation in natural springs, or secondary housing of retirees relocated after pension or prevention services for the whole population. Although frailty is the Chronicity's final stage of disease development, people with mild frailty whose rate to the Comprehensive Geriatric Assessment for Instrumental Living is quite high, are pursuing an active and healthy living and they are also travelling quite a lot.

The choice of those senior travellers is conditioned by settings that are matching their individual diseases or conditions and their care plans. The region that will prove that has the provisions for those travellers that are in similar conditions for the care that is provided to the local population as well, for them to travel safely, properly accompanied and facilitated throughout their whole journey by experienced carers and medically supervised staff, will of course attract more of those travellers over 60. The more the care is embedded in the existing care system for the local population, the larger the revenue margin will be for the care structure. If this is managed by PPP and provided by private companies that adhere to a New Care Model that

encompasses also a type of Social Contract between all parties including the segments receiving care, then there might be a solution for local authorities that have potential for Local Resource Based Community Care Development to sustain self – financed structures providing long term care to the local population in a sustainable manner. And this can function as a strong motivation for the authorities to move on and reform care to integrate services and professionals in their localities in such a way that while integrated care structures are created those to serve the facilitation of the senior travellers/dwellers segment in the area. The 1st pilot was in Greece at the region of Aegean islands. The pilot now will be transferred to UK.

#### *Methods:*

1. Extraction of epidemiological data and Risk Factors Assessment
2. VES -13 self-administered CGA questionnaire to measure i-ADL of the >65y.o. cohort. GIS mapping of population in a scale of primary and secondary prevention and care needs embedded in a care monitoring E-Health platform (existing and tested product)
3. Regression analysis of care means to the needs per CGA risk factor. Desk research analysis on the local health resources of the region
4. Alignment of the local Health and Care services and professionals of the area; drawing the lines for vision and strategy
5. Focus Groups and structured interviews to establish a Memorandum of Understanding between mayors of the area to create the Care Hub managed by Private Public Partnership with the local health ecosystem and with the Twinning and support of EU Regions with advanced experience
6. Setting the Investment Facility between the Municipal Authorities, a Bank in Greece and the public and private providers; elaborating the Business Plan of the entire Care Hub operations incl. Silver Economy service management and provision organization e.g. Senior tourism, retirement real estate, home care for senior dwellers, professionalized Living Labs, prevention services etc.
7. Proposing the Investment blending and assuring private equity, crowd funding, VC and impact investment at different stages of the Care Hub deployment until stabilization of the RoI and the cashable savings

#### *Results:*

1. Needs analysis for care service and HR for the local population delivered; primary and social care services aligned. Telemedicine for acute care and 2nd opinion deemed possible.
2. Care Hub structure and business plan delivered
3. Senior Tourism and Health Tourism model designed and delivered
4. Investment blending, investment familiarization tour to health resorts organized

Further results were compromised due to the banking crisis in Greece and the refugee crisis (as the pilot area was at the Aegean islands, entry gate of the refugee waves in 2015 and 2016) hence the relocation plans and transfer of the pilot to other touristic area of Europe, where the health and care costs are covered by the EU Social Security Regulation and the CBHD 24/2011/EC.

#### *Key conclusions:*

- 1) In order to kick off integrated care reform in a locality it is necessary to provide the means that will cover the reform cost and assure sustainability of operations in the long run.
- 2) For that it is necessary to apply a PPP structure to manage a Care Hub that will centralize organization, coordination and management of all Long Term Care services.



3) This structure does not depend on neither health nor social policy central authorities and it is run locally by a new institution built to cover both health and care for at least the primary care, social and long term care of the population. If secondary healthcare can also be aligned with hospitals and clinics this is all the better but it concerns usually advanced countries with well-organized systems, abundance of resources and investments such as Israel, N. Ireland or Netherlands for instance.

4) Investment and innovative financing and business innovation is necessary for any community care structure that wants to run sustainable care operations be it in low- middle or high income countries.

5) the first priorities to implement integrated care by order of priority are:

a. leadership awareness and on the job training

b. Deliberation of the integrated care plan with all the local health ecosystem stakeholders, not only those concerned by health sector. The vision, strategy and action plan have to be endorsed by the entire ecosystem

c. build the right investment blend until the Care Hub is sustainably run with constant RoI

d. the Care Hub management has to be independent from central authorities and abide to local control for commissioning services

e. Workforce training and patient empowerment are the next steps to engage with.

## **A comparison of three instruments (ASCOT, ICECAP, and EQ5D) for the evaluation of outcomes of long-term care services**

**Florin Vadean**

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Co-authors: Stacey Rand, Juliette Malley and Julien Forder

*Objectives:* The stated purpose of long-term care (LTC) in England is to improve the wellbeing and quality of life of service users. But how might this be measured? The National Institute for Health and Care Excellence (NICE) social care guidance recommends a flexible approach. This should include the EQ-5D measure of health-related quality of life as well as broader preference weighted measures, like the Adult Social Care Outcome Toolkit (ASCOT) care-related quality of life indicator and the Investigating Choice Experiments for the Preferences of Older People/Adults - CAPability (ICECAP-O and ICECAP-A) capability measures.

The main aims of this paper are to assess the construct validity of the ASCOT and ICECAP measures, and to comparatively assess the specificity and sensitivity of these indicators in measuring the impact of services. In particular, we aim to estimate the impact of utilisation of community-based LTC on either health-related quality of life (EQ-5D), care-related quality of life (ASCOT) and capability (ICECAP). While previous research showed that ASCOT is better suited to measuring the impact of long-term care services than EQ5D, we expect ICECAP to also capture (like ASCOT) aspects of peoples' day-to-day functioning and, therefore, effects of long-term care services.

*Methods:* Exploratory factor analysis (EFA) was used to assess the dimensionality of ASCOT and ICECAP. The intention was to determine whether the items across the instruments may load onto the same factor(s).

The impact of long-term care services on wellbeing measures was then explored using a 'production function' method. The basis of this method is that we ought to see a correlation between intensity of LTC-service utilisation and people's wellbeing ratings in a survey of service users, and these relationships can be modelled statistically. Instrumental variable (IV) estimation is used with control on observable confounders to tackle selection issues.

*Data:* A specifically-designed survey was undertaken which sampled people using publicly-funded long-term care services provided by local authorities in England. The survey provided a sample 770 service users.

*Results:* The EFA indicated that there is some overlap between the components captured by the ASCOT and ICECAP-O but not between ASCOT and ICECAP-A items. The analysis indicated that majority of the ICECAP-O items and the ASCOT 'higher order' items load into a single factor, while ASCOT items that are related to 'basic' social care needs form a separate factor. By contrast, the ASCOT and ICECAP-A do not overlap on any of the factors identified in the analysis.

We also found that LTC-service use significantly increases the care-related quality of life as measured by ASCOT, but has no significant effect when measured using EQ-5D. The effect of ICECAP is positive and significant only when excluding one capability attribute, indicated by EFA to load on a separate factor.

## **Comprehensive support for family caregivers of post-/11 Veterans in the United States: impact on Veteran health care utilization and costs**

**Courtney Van Houtven**

*Duke University and Department of Veterans Affairs, United States*

Co-authors: Valerie Smith, Duke/VA; Karen Stechuchak, VA; Susan Nicole, Hastings, Duke/VA; Matthew Maciejewski, Duke/VA; Gilbert Wieland, Duke/VA ; Maren Olsen, Duke/VA; Katherine Miller, VA; Megan Shepherd-Banigan, VA; Margaret Kabat, VA; Margaret Campbell-Kotler, VA; Jennifer Henius, VA; Eugene Oddone, Duke/VA

*Thematic area:* Unpaid carers

*Objective:* The United States Department of Veterans Affairs (VA) provides health care to 9 million Veterans in the United States. Mandated by law in 2010, The VA Program of Comprehensive Assistance for Family Caregivers (The Comprehensive Program) supports informal caregivers who care for Veterans who were seriously injured on or after September 11, 2001 while serving in the US Armed Forces and who need assistance with Activities of Daily Living or supervision or protection because of the residual effects of their injuries including traumatic brain injury, psychological trauma or other mental disorder. The Program offers a series of services and supports for the caregiver, such as health insurance, education and training, travel, lodging and subsistence, respite care and caregiver mental health services. Importantly, participating caregivers receive a direct monthly stipend ranging from \$600-\$2300. As part of a larger evaluation, the objective in this paper was to evaluate the early impact of the Comprehensive Program on Veteran health care utilization and costs (2011-2014).

*Data:* Application data; electronic health record data from the Veterans Health Administration (VHA).

*Methods:* A pre-post cohort design including a non-equivalent control group was used to understand how Veterans' acute care (emergency department, hospital care), outpatient care (primary, specialty, mental health care), and total costs changed in six month intervals 0-36 months after enrolment in the program. The control group is an inverse-propensity-score weighted sample of Veterans whose caregivers applied for but were not accepted into the program. The approach obtains the estimated average treatment effect among the treated (ATT).

*Results:* Enrolled Veterans had similar acute care utilization 0-36 months post application from those in the control group, but significantly greater primary care and mental health outpatient care use 0-36 post, and significantly greater specialty care use 0-30 months post. Estimated total costs for Veterans of enrolled caregivers were \$1500-\$3500 higher per six month interval 0-36 months post.

*Policy implications:* The Comprehensive Program was associated with increased outpatient care but not associated with increased acute care use. Increasing access to care for Veterans is a priority of the Department of Veterans Affairs, as detailed in its Blueprint for Excellence (VHA 2014). The increased outpatient utilization could be attributed to increased access to care that is facilitated by enhanced caregiver

support, or it could be that treated Veterans have increased need for outpatient care. Future work should examine longer term utilization and specific subtypes of utilization (e.g., psychiatric inpatient admissions) to provide an understanding of whether increased utilization of outpatient mental health care in the short term leads to lower utilization of emergency and/or acute care for mental health in the longer term. Examination of longer term outcomes could provide a better picture of the long-term return on investment to the Veterans Health Administration.

## **Quality of life from the perspective of older adults living at home, and the role of services**

***Miriam van Loon***

Country: Netherlands

*VU University Medical Center*

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*Thematic area:* Economics of long-term care

What are important elements of older adults' quality of life from their own perspective? How do care services contribute to quality of life according to older adults? In the ASCOT-NL project, we aim at applying the Adult Social Care Outcomes Toolkit - a measure that evaluates the influence of care services on quality of life for older adults living at home - to the Dutch context.

Current evaluation of outcomes of (social) care services and interventions for older adults living at home is limited and tends to focus on functioning and on health. This implies that attention for other relevant issues, such as contribution to achieve one's goals in a condition of limited health, is missing.

One of goals of the ASCOT-NL project is to investigate what quality of life means for older adults living at home, and to evaluate how various kinds of services contribute to their quality of life. For this part of our project, we conducted interviews with older adults living in different regions of the Netherlands.

In open-ended interviews, we first asked them about what aspects in their lives are important to them. Secondly, we distinguished four types of services that older adults receive at home: help with physical problems such as nursing care; help with mental health problems, support with social problems/activities and support and care for problems in everyday life such as housekeeping, meals services etc. Respondents who received different types of services were selected in order to analyze whether these services are important for different aspects of their quality of life.

First results show that different types of services can contribute to certain aspects of quality of life. An interesting finding at this point is how services can enable older adults to stay in their own home. Assistance with cleaning one's house, or receiving physiotherapeutic help at home, or going to an older adults' daily activity center, all contributed differently. Staying in one's own home was seen as crucial for other domains of quality of life – such as autonomy - by many respondents. Final results of the study are expected in June 2016.

Eventually, we aim to use the results for adapting the ASCOT to the Dutch context, and for evaluating whether we need additional domains in ASCOT-NL for the evaluation of certain types of services. Our goal is to implement the ASCOT-NL as policy-instrument, to guide allocation of resources in long-term elderly care in the Netherlands.

## **Who cares for the unhealthy poor rural elderly? Rural and rural disparity in home- and community-based long-term care utilisation in China**

**Wei Yang**

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*Thematic area: Equity and efficiency*

Disparity in income is one important factor leading to inequalities in health and well-being. Although a large body of research has studied the issue of inequity in health and health care in China, little is known on inequity in long-term care (LTC) needs and access to LTC among the elderly. This paper uses Concentration Indices to investigate inequity in LTC needs (i.e., Self-assessed health (SAH), Activity Daily Living (ADL) and Instrumental Activity Daily Living (IADL)) and access (i.e., informal care, all types of LTC) among the rural and urban elderly aged 60 and above. Data are drawn from China Health and Retirement Longitudinal Survey 2011. This study finds that the rural elderly has significantly greater LTC needs and higher level of unmet needs compared with the urban elderly. Among the rural elderly, the poor have greater LTC needs than the rich. LTC provision in China is still largely reliant on informal care, but the urban elderly start to use other types of LTC. Moreover, in the urban areas, after controlling for needs, significant pro-rich inequity is observed for the overall LTC use, whereas no inequity is observed for informal care use. This may suggest that the urban rich are more likely to have access to other types of LTC in addition to informal care compared with the urban poor. This study urges the policy makers to take actions to address serious shortage of home- and community-based LTC services, particularly in rural areas, and improve equitable access to these services.

## **Are recessions good for staffing in hospitals and nursing homes?**

**Rachel Werner**

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Co-authors: R. Tamara Konetzka, University of Chicago  
Karen Lasater, University of Pennsylvania  
Edward C. Norton, University of Michigan

*Thematic area: Economics of long-term care*

**Objective:** The quality and cost of care in nursing homes and hospitals depends critically on the number and quality of nurses and other direct-care staff. Recent research suggests that the nursing supply adjusts to macroeconomic conditions. That is, as macroeconomic conditions worsen and unemployment rates rise, the number of nurses in the labor force increases as job opportunities diminish and nurses use their degree to re-enter the market. This observation has been used to explain why mortality decreases during economic recessions. However, prior work has failed to account for the effect of macroeconomic conditions on demand for direct-care staff through the effect on revenues. In this study, we test how local unemployment rates affect direct-care staffing rates in both nursing homes and hospitals.

**Data:** We use two main datasets. First, to measure direct-care staffing levels in California nursing homes and hospitals, we use annual financial data files from California's Office of Statewide Health Planning and Development (OSHPD). Second, to measure county-level unemployment rates we use the Area Health Resources File (AHRF). We then confirm our findings in nursing homes across the United States, obtaining staffing data from the Online Survey and Certification Reporting (OSCAR) data set.

**Methods:** We exploit the wide variation in the unemployment rate within counties between 2001-2012 and use a longitudinal fixed-effects strategy to examine how the local unemployment rate affects direct-care staffing levels at nursing homes and hospitals. We analyze the effect of annual county-level unemployment rates on direct-care staffing levels using a linear model with facility and year fixed effects. Thus, identification

relies on within-facility variation in our outcomes. We also test whether there are heterogeneous effects of unemployment rates by facility size, staffing level, and profit status.

*Results:* In California nursing homes we find that as unemployment rates increase, staffing by registered nurses (RNs) decreases but staffing by licensed practical nurses (LPNs) increases. The increase in LPNs is larger in small nursing homes, nursing homes with higher staffing levels, and in not-for-profit nursing homes. In California hospitals, on the other hand, we find no statistically significant effects of unemployment rates on staffing levels. When examining the effect of unemployment rates on net revenue, we find that higher unemployment rates is associated with lower but not statistically significantly different net revenue overall in both nursing homes and hospitals. In stratified regression in nursing homes, an increase in unemployment was associated with positive net revenue for small nursing homes, nursing homes with high staffing levels, and not-for-profit nursing home.

*Implications:* While the effect of macroeconomic conditions on nursing supply may be important for cost and quality of care, the mechanism is not simple, direct, or homogeneous for all types of nurses and providers. Additionally, the macroeconomy affects hospitals and nursing homes differently. This may be due to the fact that the demand for nursing home care is more sensitive to the economy than for acute care services because elderly have far more complete insurance for acute care.

## **Person-centredness in long-term care services for older adults: a systematic review of survey measures and measurement properties**

**Mark Wilberforce**

*University of Manchester, United Kingdom*

*Thematic area:* Personalisation of the care system

*Background:* ‘Person-centredness’ is internationally regarded as a central component of modern health and social care services. Despite attaining such prominent status, it is notoriously difficult to conceptualise and measure. Without good measurement, the scientific value of person-centredness is compromised, and providers are unable to evaluate the performance of their services with any confidence. No systematic review has so far been undertaken, and the few narrative reviews suffer from inadequate critical appraisal of methods.

*Objectives:* To identify, describe and critically appraise survey-based instruments that purport to measure person-centredness in the long-term care of older adults.

*Methods:* A systematic review of survey-based measures was undertaken. In addition to extracting details of measurement properties, the review critically appraised the methodological quality of the studies underpinning them. The COSMIN toolkit (COnsensus-based Standards for the selection of health Measurement Instruments) was used to synthesise the results.

*Results:* Eleven measures tested in 22 references were included. Six measures were designed for use in long-stay residential facilities, and four were for ambulatory clinic-based care. Only one measure was designed chiefly for evaluating home care services. The measures rarely incorporated service user or carer perspectives in devising the questionnaire items.

Overall, measures were tested only in relation to a narrow range of psychometric properties, and the rigour of these estimates were consistently undermined by poor methodological quality. Testing of hypotheses to support construct validity was of particularly low standard, whilst measurement error was rarely assessed. Furthermore, measures were too-often translated into new languages before rigorous properties had been established in the original tongue. Two measures were identified as having been the subject of the most rigorous testing.

*Implications:* Policy-makers are increasingly concerned that providers should attend to care experiences, as a crucial component of overall quality. Person-centredness is a helpful concept that places experiential

features of care at the front-and-centre of service design. To evaluate care quality in this regard requires robust measures, but those reviewed in this study cannot be unequivocally recommended. Future research should pay greater attention to methodological rigour. The lack of service user and carer involvement in instrument design is poor practice (and ironically incompatible with person-centredness). Researchers may, in future, prefer to test a narrower-range of measurement properties in any single study, but do so to a higher standard.

## **The effect of frailty and cognitive impairment levels on formal and informal care time for older adults in the community**

**Gloria Wong**

Country: Hong Kong

*The University of Hong Kong*

Co-authors: Mandy Lau, The University of Hong Kong

Jennifer Tang, The University of Hong Kong

Terry Lum, The University of Hong Kong

*Thematic area:* Economics of long-term care

*Objective:* Community care requires varying resources input that is mainly affected by a person's frailty level. Less well understood is the variation in the respective contribution of formal and informal care, and whether it is affected by frailty and cognitive levels. This study investigated formal and informal care time in a community case-mix sample.

*Data:* Formal and informal care time (in hours) was collected over a 4-week duration. Information about frailty and cognitive level was collected using the interRAI-HC 9.1 instrument, and categorized by resources utilization groups (RUGs) and Cognitive Performance Scale (CPS).

*Methods:* Cross-sectional staff-time measurement (STM) study with participants recruited from day care and home care services units in Hong Kong according to the territory's current service user ratio in each service.

*Results:* A total of 298 community care service users participated. The informal-to-total care time ranged from 0.16 to 0.50. Participants in the RUG groups of 'Extensive and Special Care' and 'Clinically Complex with high ADL Need' had the highest informal care time ratio. While total care time substantially increased from cognitively intact to very severe impairment on CPS, informal care time ratio remained high throughout, at over 0.8 across impairment levels.

*Policy implications:* Policies aiming at supporting ageing-in-place and rational interfacing between community and residential care should take into account the disproportionate contribution of informal care as levels of frailty/resources utilization increase, in particular for people with cognitive impairment.

## **Home care for older people in urban China: impacts of the marketisation process**

**Wenjing Zhang**

*University of Bristol, United Kingdom*

*Thematic area:* LTC in LMIC countries

The reforms of care for older people have been embarked upon in urban China as a result of the dramatic demographic and social-economic changes that have taken place since the 1980s. Home care is proposed to fulfil the rising care deficit for older people, while the market plays an increasingly active role in the field of care in urban China. Although various strategies of marketisation have been applied in financing and service provision in urban China, few studies pay attention to the marketisation of home care. This exploratory study aims to examine how the marketisation process is shaping the development of home care policy and practice for older people in urban China. The primary objective is to explore the model of the marketisation of home

care in urban China. This leads to the following objectives: examine the rationale behind the marketisation of care; understand the marketisation trend of home care; discuss processes of marketisation of home care; and explore existing and potential impacts on the care system and participants in the care market. Five key stakeholders are identified in the home care market in urban China, namely service users, providers, purchasers, care workers, and regulators. Central to this case study is experiences and viewpoints of service providers and local regulators in Shanghai, who have first-hand information about how home care agencies are organised, how government policies are implemented, and what kind of marketisation processes are proposed. Semi-structured interviews with managers in home care agencies and local public officials are the main data source, supplemented by policy documents. The marketisation of care in urban China is distinctly based on its strong state, the traditional emphasis on family, state-based community, and increasing market involvement. This study explores the role of service providers and local regulators in the policy process, as well as identifies the characteristics embedded in the policy and practice of home care for older people. Key strategies have been applied in the trials of marketisation of care in Shanghai: 'contracting out' from the state to independent providers, cash or noncash financial support to older people and family for purchasing care services and employing care workers, and direct purchasing in the care market through private funding. This study discusses the impacts of the marketisation of care for older people on care recipients and providers and shifts of the care diamond, under the themes of equality, competition, efficiency, quality, care relationships, and shifts of care regime.

# Organised Sessions

## Organised session 1:

### Improving health services for UK care homes – evidence, experience and education?

**Session organisers:** *Barbara Hanratty, Claire Goodman, Karen Spilsbury and colleagues*

#### Session overview

In England, innovation and integration of services are the central tenets of recent policy aimed at improving health in social care. Significant financial investment has been made in six locations (vanguards), to develop new models of care that could be replicated across the country. The pace of change is rapid and expectations are high, with hopes that the vanguard programme will provide a blue print for the future survival of a financially constrained health and social care sector.

In this session, we will juxtapose research findings with current experiences in one care home vanguard site. First we will present the mechanisms and components of service delivery to care homes identified as key, by an academic research study (OPTIMAL). These will be contrasted with the understanding, expectations and experiences of stakeholders in the Gateshead care home vanguard site, northern England. The third and fourth presentations will consider how the care home workforce may need to change to underpin innovation, using the findings of a Delphi study on core skills and education for care home nurses and a systematic review of the evidence for medication management by care assistants.

This session will highlight the relationship between research evidence and the reality of service innovation and integration.

#### **Presentation 1: The Gateshead Care Home Vanguard – towards a realist evaluation**

*Objective:* The Gateshead care home vanguard is a complex programme, combining service realignment, a new care pathway, formation of a provider alliance network, outcome based commissioning and a workforce development strategy. The aim of this study was to establish a clear understanding of the programme as it was developing and the underlying assumptions and expectations about how it will produce change, in the local context.

*Methods and results:* We conducted semi- structured interviews (n=30) in February and March 2016, with senior decision-makers in the Gateshead Vanguard team and partner organisations; national decision-makers in NHS England; key members of the local health economy, including care home managers, GPs and nurse leaders. Topics included the main enablers, barriers, contextual factors necessary for successful development and implementation of the programme; how success should be judged, and the appropriateness of national evaluation metrics to the local context. Interviews were recorded, transcribed and subject to thematic analysis. These data were supplemented by a content analysis of documents produced by the care home vanguard and NHS England, and a stakeholder workshop. Findings will be presented at the ILPN conference.

*Policy implications:* This work will provide insights into the size and nature of the challenge faced by innovators in the complex, mixed economy of care homes. It will also identify policy priority questions to address in any evaluation of the developing care home vanguard programme.

#### **Presentation 2: What supports effective working within and across different models of health care provision to care homes: findings from the OPTIMAL study**

*Objective:* The heterogeneity of the care home market and localised approaches to the provision of primary and community care means it is unlikely that one model of service delivery will be suitable for all settings. The aim of this study was to understand what supports effective working within and across different models of health care provision to care homes



**Method and Results** Using realist methodology we completed an evidence synthesis to determine what, within different models of care might determine success and failure in care home settings in relation to five outcomes: residents' medication use, use of out of hours' services, hospital admissions and length of hospital stay, costs and user satisfaction. The synthesis findings of what works when and in what circumstances were tested in three sites with different approaches for health care delivery to care homes. Residents' care in 12 care homes (n=242) were tracked for 12 months with resident, relatives and visiting and care home staff interviews (n=130). Findings identified key mechanisms within different service models that were likely to increase (or reduce) staff and resident satisfaction and use of NHS services. Financial incentives for GPs and investment in dedicated services were an important resource but were not of themselves sufficient to change working relationships and behaviours.

*Policy implications:* Models of service delivery to care homes are many and ill-defined. An understanding of the likely mechanisms that generate conditions for effective working between primary/community health and residential care is key for planning future health care provision to care homes.

### **Presentation 3: Priorities for the care home nursing workforce**

*Objective:* To establish a consensus view on the training and professional development needs of registered nurses employed by UK care homes

*Methods:* A two stage, online modified Delphi study with a panel of experts (n=352) representing: (i) care home nurses and managers; (ii) community healthcare professionals (including general practitioners, geriatricians, specialist and district nurses); and (iii) nurse educators in higher education.

*Results:* The consensus was that registered nurses in care homes require particular skills, knowledge, competence and experience in order to provide high quality care for older residents. The most important stated responsibilities for the care home nurse were: promoting dignity, personhood and wellbeing, ensuring resident safety and enhancing quality of life. Priorities for continuing professional development (CPD) included personal care, dementia care and managing long-term conditions. The main barrier for care home nurses accessing CPD was staff shortages. Nursing degree programmes were perceived as not adequately preparing nurses for care home nursing.

*Policy implications:* If care home nurses are not fit for purpose, the consequences for the rest of health and social care are significant. Care homes, the NHS and educational authorities need to work together to provide challenging and rewarding career paths for registered nurses and evaluate them. Without well-trained, motivated staff, high quality of care in residential settings will remain merely an aspiration.

### **Presentation 4: Administration of medicines in care homes (with nursing) for older people by care assistants – developing guidance for care home providers**

*Objective:* To develop evidence-based guidance on the role of the care assistant in medicine administration in UK care homes with nursing for older people. We have focused on this particular care home setting in response to the brief: to consider how the registered nurse in this environment could be 'freed up' from medicine administration to focus on case management of residents with complex needs, undertaking assessments of need and the supervision of care staff in the provision of care.

*Methods:* We have conducted a 'rapid review' of literature on the administration of medicines in care homes (with nursing) for older people by care assistants and related relevant legislation and policy documents. Our focus, for the purposes of the review and the development of subsequent guidance, is UK literature but this is located within an international context. Our framework for conducting the review ensures that the methods deployed are conducted in a rigorous and transparent way. Thirty-two UK papers are included in the review. The majority of the included literature (n=23) comprises: legislation, regulation, professional standards, standards and guidance from national bodies and organisations, improvement projects and audit, descriptive articles from the care sector and news items. Only nine research papers provided findings of relevance to the focus of this review.

*Results:* The review has informed the development of guidance for care home providers on the role of the care assistant in medicine administration in care homes (with nursing) for older people. The law does not prevent care assistants from administering medicines in care homes. However, there is legislation, guidance, professional standards and evidence that inform the roles and responsibilities of the registered provider and individual staff (Registered Nurse and Care Assistant) involved in medicine administration. This broad ranging literature will be discussed and related to the evidence-based guidance that will be shared in this presentation.

*Policy implications:* There is a workforce crisis in the care home sector. Considering ways to 'free up' time of the registered nursing resource is a priority for care home providers, practitioners and policy makers. This presentation will address uncertainties about the role of care assistants administering medicines in care homes with nursing for older people. This provides an opportunity for the care home workforce to reconsider roles and responsibilities that may enhance the care for residents through timely administration of medicines and promoting the role of the registered nurse in important areas of care, such as case management.

## **Organised Session 2:**

### **The views of Americans on social care: results from the 2014 Survey of Long-Term Care Awareness and Planning**

**Session organiser: Joshua Wiener**

*RTI International, United States.*

**Discussant: Tamara Konetzka**

*University of Chicago, United States*

#### **Session overview**

The current American system of financing social care is broken, with a heavy dependence on means-tested programs and out-of-pocket spending rather than insurance. With the aging of the population, the number of people requiring social care is certain to grow dramatically. This research panel will present new analyses of the U.S. Department of Health and Human Services-sponsored Survey of Long-Term Care Awareness and Planning. This 2014 survey was conducted with a national sample of noninstitutionalized persons age 40-70 participating in the web-based KnowledgePanel®. KnowledgePanel represents a random selection of the American population. The survey had a response rate of 66%, yielding a total of 15,298 respondents.

Papers will focus on four topics: First, what is the experience of the population with social care, their knowledge about these services and their costs, and their perception of needing nursing home care? Second, what are the concerns of Americans regarding their potential need for social care and what are they willing to do if they need services? Third, what public policies do people support regarding potential social care financing reform? And, finally, what features of long-term care insurance policies are most important to people and what are they willing to pay for coverage? For the last paper, survey respondents were asked to participate in a discrete choice experiment in which they were asked to choose between insurance policies with different characteristics or no policy.

#### **Paper 1: What do Americans know about social care?**

**Galina Khatutsky**

*RTI International, 307 Waverly Oaks Rd, Waltham, Massachusetts USA 02452*

Co-authors: Joshua Wiener, Trini Thach, Angela Greene

The lack of the public's understanding of the risks of needing social care, the costs, and how public and private programs work is related to inadequate preparedness for these risks. Using Long-Term Care Awareness and Planning Survey data, this study finds that knowledge of social care is low among those aged 40 to 70. Less than a quarter of respondents correctly estimated the average cost of nursing home and home care in their state, although 53% reported some personal social care use by relatives or friends. People tend to overestimate their longevity but underestimate their future need for services. Only about a quarter of respondents knew the government program that pays the most for social care. Better understanding of the gaps in knowledge about social care may be a precondition to better personal and societal planning.

#### **Paper 2: What are Americans' primary concerns about becoming disabled, and how are they acting or willing to act on those concerns?**

**Angela Greene**

*RTI International, 3040 Cornwallis Rd, Research Triangle Park, North Carolina USA 27709*

Co-authors: Trini Thach, Joshua Wiener, Galina Khatutsky

With the aging of the U.S. population and the higher prevalence of chronic illness and disability, understanding what concerns Americans have about becoming disabled and using social care and what

actions they are willing to take should they need social care is increasingly important. A key issue is understanding what concerns motivate people to develop a plan to address possible disability. Using data from the Survey of Long-Term Care Awareness and Planning, we find high very levels of concern about affording social care, ability to choose the type of social care, losing independence, and being a burden to family. The most popular options for social care actions were to make modifications to homes; rely on spouse, family or friend; or have family or friend move in. Few people were willing to use home equity to pay for care or to move to a nursing home.

### **Paper 3: Social care financing options in the United States: who is responsible and which options do people support?**

**Joshua Wiener**

*RTI International, Washington, DC, USA*

Co-authors: Galina Khatutsky, Angela Greene, Trini Thach

This paper assesses attitudes of the general population regarding financing social care in the United States. Using data from the Long-Term Care Awareness and Planning Survey, we find that most people supported individual responsibility and voluntary options. Approximately 62 percent of respondents said that they 'strongly agree/agree' with the view that it is the responsibility of individuals to finance their social care; conversely, about 37 percent of people stated that they 'strongly agree/agree' with the view that it is the responsibility of government to help pay for social care. Among policy options presented, about two-thirds of respondents supported tax incentives or other mechanisms to encourage private long-term care insurance. While only 18 percent of respondents supported a mandatory public long-term care insurance program, support for a voluntary public insurance program was high. Distrust of government to run a public long-term care insurance program (53 percent) was higher than distrust of private insurers (32 percent). Unexpectedly, there were few differences by sociodemographic characteristics.

### **Paper 4: What do Americans want in long-term care insurance policies? Results from a discrete choice experiment**

**Joshua Wiener**

Co-authors: Derek Brown, Washington University, St. Louis, Missouri, USA; Benjamin Allaire, RTI International, Research Triangle Park, North Carolina, USA

To assess preferences for features of long-term care insurance (LTCI) policies and programs, a discrete choice experiment was conducted as part of the Survey of Long-Term Care Awareness and Planning. The most important insurance features to respondents was duration of benefit, followed by premium cost, and benefit amount (e.g., \$150 a day). Weaker preferences were found for plans with no medical underwriting requirements. No statistically significant results were found for deductible amount. Voluntary participation was strongly preferred over mandatory participation, although additional benefits in mandatory plans could compensate people for their preference for voluntary participation. Nearly one-third of respondents always picked the least expensive plan, and 15% of respondents preferred no insurance under all scenarios including those at lowest premium monthly cost shown. Preferences suggest that people are often not realistic in evaluating the tradeoffs among insurance policy characteristics, especially related to cost. Implications for the design of public and private insurance are discussed.

## **Organised session 3:**

### **Marketization: the growth and impact of large for-profit nursing home chains**

**Session organiser: Charlene Harrington**

*University of California San Francisco*

#### **Session overview**

The trend in the marketization of long term care has been occurring in many industrialized countries. This symposium focuses on the growth and impact of large for-profit nursing home chains in the U.S., Ontario, the U.K., Norway and Sweden. By examining descriptive and statistical data on the five largest for-profit nursing home chains in each area, we show trends in their growth in size and revenues and the complex ownership models that have been developed. Although access to financial and quality data from these large corporations are limited, we describe some of the impact of these trends in each location and some economic, political, regulatory, and social policy issues that must be considered by researchers and policy makers.

### **Paper 1: Marketization: ownership, financing, and quality in the five largest U.S. for-profit nursing home chains**

Co-authors:

**William Hirst**, Barts and the London School of Medicine and Dentistry

**Allyson Pollock**, Queen Mary, University of London

**Frode Jacobsen**, Center for Care Research, Bergen University College

Over the past two decades, the number of beds owned and managed by large nursing home chains in the US has grown steadily. Of the total 15,600 U.S. nursing homes, almost 70 percent are for-profit and 56 percent are owned by chains with two or more facilities. Of the 1.4 million residents in U.S. nursing homes, 15 percent were under age 65 and 65 percent had cognitive impairment.

*Objective:* This study was designed to examine the ownership and financing of the 5 largest for-profit U.S. nursing homes chains in 2014 and to compare selected quality measures for those chains with those of other nursing home ownership groups for the period of 2010-2014.

*Data and methods:* Descriptive data on ownership, revenues, expenses, profits, and litigation were collected for the 5 largest for-profit nursing home chains from annual reports and other documents. Statistical data from government sources on (1) nursing staffing levels and (2) quality measured by violations of regulatory requirements were compared for the 5 largest nursing home chains with other ownership groups.

*Results:* The 5 largest for-profit chains each have between 24,000 and 55,000 beds in 200 to 453 facilities and they owned 9 percent of total nursing homes and 10 percent of total beds in the U.S. in 2014. The largest U.S. chain merged with the fifth largest chain and two other large chains between 2010-2015. The other four largest chains remained fairly stable in size over the period. Annual revenues in each chain grew rapidly and varied from about \$1.3 to \$5.6 billion in 2014. These large chains had higher percentages of their revenues from Medicare and private pay than the average nursing home, and some reports showed high profit margins.

All of the 5 largest chains were owned by private companies or private equity firms and one chain also owned a publicly-traded nursing home company. Each chain had complex ownership arrangements with each nursing facility assets owned by separate property companies and separate operating companies. Reporting of ownership and financial data on revenues, expenditures, and profits was very limited by the private companies.

In terms of quality measures, the largest for-profit chains had the lowest registered nurse and total nursing staff per resident day compared to other non-profit and government facilities. In addition, the largest chains had more quality problems. They had the highest number of total deficiencies and serious deficiencies per facility compared to non-profit and government facilities, that had the lowest numbers in the 2009-2014 period. Some of the largest chains had litigation actions for fraud filed against them by the federal government.

*Policy implications:* Overall, the profit-oriented strategies of large chains appear to conflict with goals of providing high staffing and quality of care to residents. Moreover, the ownership and financial transparency of large for-profit chains, especially those owned by private equity companies is very limited.

## **Paper 2: Care for sale: privatizing long-term care in Ontario**

**Justin Panos**

The marketization of long-term care has been a recurrent issue in Ontario. With about 630 homes and over 77,000 beds, over half of the sector is controlled by private for-profit companies. Over the last four decades, the consolidation of ownership has resulted in the rise of five distinct corporate care chains. These chains own between 25% and 33% of care homes. Despite two large reforms to long-term care, including legislative overhaul in 1998 and 2007, and increases to operating and capital costs, quality of care and understaffing continue to be a core issue.

*Objective:* The purpose of this study is to assess the impact of marketization on quality and cost of nursing care homes. It examines the trends of privatization in Ontario since the enforcement of the Long Term Care Homes Act in 2010 (LTCHA).

*Data and methods:* This paper examines descriptive data such as newspapers, wire reports, annual financial reports, third party research and government reporting on the five largest care home chains. It also uses government statistical data to critically examine staffing levels and other deficiencies. It provides an assessment of profit level indicators across ownership types and the mechanisms of finance and profit.

*Results:* Combined, Ontario's five largest chains were transferred \$4.3 billion (Canadian dollars) between 2010 and 2015. Mergers and acquisitions in this sector have been predominant since the LTCHA. The largest chain, Revera Inc, is a for-profit chain fully owned by the Public Sector Pension Investment Board, a crown corporation of the federal government. The merger of Specialty Care and Leisureworld formed, what is now the second largest facility, Sienna Senior Living. Third in size is Extendicare, who continue to pursue acquisitions and become involved in non-profit homes. Chartwell has seen steady growth through the construction and acquisition of many retirement homes by Spectrum Seniors Housing Development LP. They have also enhanced their presence in remote Northern Ontario. In fifth, Schlegel Villages has aggressively expanded through public-private partnerships in the human health services and the university sector. It is the only family owned firm among the top five and is not subject to the financial accountability of publicly traded firms and REITs.

*Policy implications:* Mergers and acquisitions require the build up of large debts, which are eventually repaid through corporate restructuring. This imperative of financialization has created numerous obstacles to adequate funding for staff. The rates of physical and chemical restraints were high in Ontario until public backlash forced the government to take adequate steps toward behavioural supports. Local governments have chosen to contract out services while maintaining municipal ownership for the time being. The non-profit sector has been withered by the government's withdrawal of certain funding advantages like tax breaks, favourable capital subsidies and higher per diems. Combined with total austerity across public sector wages, the crisis of understaffing shows no signs of abating.

## **Paper 3: Marketization: the growth and impact of large for-profit nursing home chains: UK perspective**

**Allyson Pollock, Shailen Sutaria, William Hirst**

Over the past 40 years, the UK has undergone rapid transformation of the care home industry from predominately public sector ownership to predominately private sector ownership. In 1970 30% (84,100 beds) of beds were non public owned; by 2014 this had risen to 93% (453,000 beds). Following rapid expansion of the private industry, the last 15 years has seen increasing consolidation of the private sector with the emergence of large care home providers. We track the expansion of the current 5 largest providers of long-term care.

*Objective:* We aim to: (1) Describe and examine the method of growth of the 5 current largest providers of long-term care; (2) Describe and examine company structures, finances and strategy; and (3) Examine the transparency and quality of care provided by the 5 largest providers.

*Data and methods:* We collate and examine publically available data from a range of sources including: companies' accounts, government inspection data and published financial articles.

*Results:* Currently, the top 5 largest providers of residential beds in the UK: Four Seasons Health Care, Bupa Care Homes, HC-One Ltd, Barchester Healthcare and Care UK; account for 20% of available residential beds. All except BUPA Care Homes are private limited companies responsible to shareholders, ultimately controlled and owned by private investment and equity groups registered in Jersey or Cayman Islands. All demonstrate complex ownership with multiple subsidiaries and separation of operating and property components; resulting in limited financial transparency. Prior to 2008, expansion was driven by mergers and acquisitions funded by debt; with private equity groups attracted by stable government funded income, increasing property prices of homes and advantageous demographic changes. Post 2008 global financial crisis, with a fall in property prices and poor income, focus has been on diversification and restructuring – separating operations and property ownership, and selling of less profitable care homes and development of new care homes in more affluent areas. Multiple concerns regarding the quality of care homes owned by corporate chains have arisen in the media. We will additionally report on the quality of care homes owned by private sector using data from government inspection.

*Policy implications:* The UK care home industry is in crisis and needs urgent reform. The purposeful build up of large debt to fund growth has resulted in unsustainable debt repayment. Complex structures and lack of financial transparency hinder accountability. Despite the failure of marketization in long term care, currently government policy does not attempt to limit further marketization, and more widely introduces marketization in healthcare.

#### **Paper 4: Marketisation in Scandinavian welfare states: the role of large corporations in residential care for older people**

**Frode F. Jacobsen**

Co-author: Marta Szebehely

In the context of the Scandinavian tradition of universal, tax-financed care services, centred on public provision, the recent wave of marketisation and the increasing role of for-profit companies in residential care for older people might be unexpected. However, Sweden and Norway, with fairly similar welfare models are not affected to the same extent. In Norway, 6 per cent of a total of 41,000 beds in residential care are run by for-profit providers, in Sweden around 18 per cent of 90,000 beds. Even if the proportions are comparatively small in an Anglo-Saxon context, the growth is considerable given that there were no for-profit actors in Scandinavia before the beginning of the 1990s. Of particular importance is that in both countries, large international corporations increasingly dominate the market. Starting in Sweden in 2005, these corporations were bought up by private equity firms but more recently there has been a gradual shift away from a dominance of private equity.

*Objective:* The aim of this paper is to describe and analyse the largest for-profit actors in Norway (4) and Sweden (5) residential care for older people with a focus on size, activities, ownership and revenues from 2000 to 2015.

*Data and methods:* Multiple sources of data are investigated, such as annual reports, union reports, national statistics, third party research and mass media reports

*Results:* In Sweden, half of the beds in for-profit homes are run by the two largest corporations, Attendo (95 homes, 4250 beds) and Ambea (86 homes, 3940 beds). After those two biggest companies, the next group includes Aleris (34 homes), Förenade Care (32 homes) and Norlandia (11 homes). In Norway, the four largest corporations run 3/4 of the for-profit beds, Aleris (9 homes, 544 beds), Unicare (6 homes, 543 beds), Norlandia (5 homes, 424 beds) and Attendo (6 homes, 308 beds). Several companies are running businesses in both countries: Three of the five largest companies in Sweden are among the top four in Norway (Attendo, Aleris and Norlandia), and in both countries, the big actors are increasingly active in other areas such as health care, disability services or recently arrived minors seeking asylum. Taking these different activities and the Nordic

countries together, the largest actor Attendo has 14,000 employees, the second largest Ambea has 10,000 and the third largest Aleris 6,600.

*Policy implications:* All the companies have a complex ownership structure, and the mother company is usually based in a tax haven. As a result, all the large companies report low return on assets and low profitability, and they all pay very little tax in Scandinavia. This has raised political concern in both countries; in Norway a shift in political majority (to the left) in some of the larger municipalities has led to local decisions to stop out-sourcing to for-profit actors, and in Sweden a government commission is investigating possibilities to limit profit making in welfare services. In contrast to Sweden, no companies own buildings or other material assets in Norwegian residential care which makes it easier to end contracts in Norway.



## **Organised session 4:**

### **Bridging aging and disability sectors to improve community-living outcomes for persons aging with and aging into disability**

***Session organiser: Michelle Putnam***

*School of Social Work, Simmons College, Boston, MA, USA*

Session overview: More persons who were born with or acquired disability in early or mid-life are now living into old age. This new aging demographic reflects advances in medicine and rehabilitation, social welfare policies, and advocacy for rights and inclusion by persons with disability and their families. Ageing and disability service sectors, however, retain historical segmentations that tend to limit efficiency and effectiveness of service and program delivery, use different operational models, and draw on different evidence bases. The bifurcation of ageing and disability sectors has implications for all adult with disabilities, but particularly for those ageing with long-term disability. This session presents three papers that discuss the issue of bridging ageing and disability and the role of policies in both dismantling and contributing to this segmentation. The first paper explores the role of financial and regulatory incentives to facilitate intersectoral collaboration between health and social care sectors paying specific attention to the impact of these incentives on health and disability outcomes. The second paper presents data from the EU PATHWAYS Project's assessment of employment policies across European welfare models and in 10 countries discussing their implications for persons aging with versus aging into disability. The third paper describes the evidence base related to aging with disability and long-term services and supports and the implications the state of this segment of research-based knowledge has for U.S. LTSS policies as the federal government increases its preference for funding (sometimes only) evidence-based interventions and programs.

#### **Presentation 1: Limitations in the evidence base for long-term services and support and persons aging with long-term disability: implications for U.S. programs and policies**

***Michelle Putnam***

*Objective:* Evidence-based practices and programs are quickly becoming preferred for funding by the U.S. federal government over non-evidence based long-term services and supports (LTSS) models and interventions. In 2016, the federal government raised its standards for levels of evidence required for an intervention to qualify as evidence-based. At the same time, there has been a dramatic shift in requirements for increasing access to home and community-based care for persons with disabilities of all ages and reducing institutional care placement. Thus there is a demand for more and better evidence-based interventions at the same time there is a much wider domain of care settings and options available. Additionally, this increased demand comes at a time when the population of persons with disabilities is diversifying, particularly in later life, as the numbers of adults aging with early and mid-life onset of disability are living longer.

This presentation examines the depth and breadth of the evidence base relating to LTSS and persons entering later life with lifelong disability or disability acquired in early or mid-life. It reports the findings of a scoping review that aimed to identify the amount, type, and nature of the peer-reviewed research evidence that directly focused on aging with long-term disability populations and long-term services and supports (LTSS).

*Data and methods:* Data collection included a systematic search of electronic databases including PubMed, Web of Science, SocIndex, PsychIndex, CINAHL, and the Cochrane Database of Systematic Reviews. Inclusion criteria were a studies in English, study samples that consists of adults 45 and older with disability or impairment onset prior to age 60, and study aims and/or focus related to LTSS. Studies were excluded if they were primarily bio-medical. Articles published between 1995 and 2015 were reviewed.

*Results:* Results indicate that the evidence base related to LTSS and persons aging with long-term disability is relatively small with most articles addressing issues of caregiving, dementia, life transitions, and health and wellness. More research literature exists relating to persons aging with intellectual disability than persons

aging with physical disability. With the literature, there were few intervention studies or evidence-based practices identified. Significant gaps in the literature suggest the need to focus efforts on building a stronger evidence base to support the development of LTSS practices for persons aging with long-term disabilities.

*Policy implications:* Given the federal government's shifting emphasis on funding evidence-based practice in LTSS, there is a need to build a stronger evidence base to support adequate and effective LTSS provision to adults aging with disabilities. In not doing so, persons aging with disabilities are likely at risk for poorer health and wellness outcomes than their peers who are aging into disability (acquiring sustained disability for the first time in later life) and are the more traditional research population for evidence-based practice with older adults. Given the many current national initiatives to improve LTSS outcomes, to support aging in place and community-based living, and to address rising LTSS costs, more LTSS research that includes persons aging with disability should be undertaken.

## **Presentation 2: Ageing and disability: the role of financial and regulatory incentives in facilitating intersectoral collaboration**

***David McDaid and A-La Park***

Personal Social Services Research Unit, London School of Economics and Political Science, London, UK

Many individuals with long term disabilities are now living to old age, while ageing itself is associated with an increase in functional limitations and disabilities. Potentially there are benefits to be gained not only by sharing knowledge and experience but also through better collaboration for the delivery of long term care and support. Examples of opportunities for greater collaboration include supporting people with a disability to 'age in place' like other members of the general population and in moving to appropriate residential care when their needs change and can no longer be supported in the community. Older people ageing into disability may equally be able to benefit from some of the supports and innovations that have been used to support younger people with disabilities to help maintain independent living. Historically, however, there have been significant structural and practical barriers to between ageing and disability structures and organisations.

This presentation looks at how financial and regulatory incentives can be used to facilitate intersectoral collaboration and partnership working. It reports on findings from a systematic review that examined evidence from the last decade on different funding and regulatory mechanisms to promote intersectoral collaboration including between ageing and disability organisations and structures. Eight databases were searched: Medline, CINAHL, Psycinfo, ERIC, Business Source Complete, the International Bibliography of the Social Sciences (IBSS), the Social Care Institute of Excellence database and Econlit.

This review indicates that there is now a significant literature on financing arrangements to help facilitate joint actions between the health and social care sectors; however there are few examples of how the pooling of budgets and regulatory agreements for joint working have been used explicitly to bring the ageing and disability sectors together. These examples do suggest that the pooling of funds can in some circumstance help reduce administration and transaction costs, generating economies of scale through pooling of staff, resources and purchasing power, and facilitating more rapid decision-making. There appears to have been relatively little focus on assessing the impact of these measures on final health and disability-relevant outcomes.

Key indicators for success in bridging include the way in which arrangements for joint funding have been developed; arrangements that are voluntary in nature take more time to develop but appear to be more stable than mandatory arrangements imposed by government. Co-location of staff and functions of agencies sharing budgets is another facilitator. Quantifying the economic costs and benefits of enhanced intersectoral working is also helpful in building support for cooperation when benefits to both the disability and ageing sectors are highlighted. Disability and ageing sector partners need to perceive the pooling of resources to be in their own interests, adding value to what they can achieve in isolation.

### **Presentation 3: How legislation impacts on aging with disability an aging into disability: The EU PATHWAYS project's results from the perspective of employment sector**

**Matilde Leonardi**

Co-authors: C. Scaratti, on behalf of PATHWAYS Consortium, Foundation IRCCS Neurological Institute 'Carlo Besta', Milan, Italy

In the years ahead disability will be an even greater concern to developed and developing nations due to aging populations, higher risk of disability in older people, as well as the global increase in chronic health conditions, such as diabetes, cardiovascular disease, cancer and mental health disorders. Non communicable diseases (NCDs) are broadly defined by the World Health Organisation (WHO) as diseases of long duration and generally slow progression that are not passed from person to person. NCDs pose a serious threat to society and future development as they are responsible more deaths and disability than all other causes together. The dual phenomena of global aging and increased longevity for individuals with disabilities represent new challenges for the 21st century. These include: strains on pension and social security systems; preparing health providers and societies; preventing and managing age and disability associated secondary conditions and chronic diseases; designing sustainable policies to support healthy aging and community-living as well as long-term and palliative care; and developing disability and age-friendly services and settings.

The last issue is where the EU Pathways project fits in as it aims at identifying and improving European strategies for professional integration and reintegration of persons with chronic diseases and mental health issues. The burden of chronic diseases is high and virtually impacts on all aspects of individuals' lives, affecting also ability to work, earnings, job turnover. NCDs are also closely linked to growing state expenditures on disability benefits. Persons with NCD-related impairments of working capacity or health can be recognized as disabled by their governments and thus be eligible for disability pensions.

One of the main objectives of the project is to map existing strategies used in Europe to provide employment support to persons who may have difficulties to find a job and to work due to their long-term health problems/disability. Pathways has mapped available policies in Europe and in 10 countries: Austria, Czech Republic, Germany, Greece, Italy, Norway, Poland, Slovenia, Spain and United Kingdom. The countries represent the five European welfare models: Scandinavian, Continental, Anglo-Saxon, Mediterranean, and 'Post-Communist'. Identifying strategies in countries from different welfare models allows exploring potential commonalities and differences and identifying possible trends in the region. Strategies considered in this study are at the level of policies, systems, and services.

Results showed that people affected by NCDs represent a 'grey zone': when they enter the category of persons with disabilities, depending on the legislation of individual countries, they benefit of the employment strategies for persons with disabilities. However when people with NCDs do not fall into the category of persons with disabilities they are not covered by employment services, systems and policies.

Lessons learned from the case of legislation on employment for people with NCDs should be used as a key factor for the need to better plan strategies for aging with disability and aging into disability international trends.

The EU PATHWAYS project received funding from the European Union's Health Programme (2014-2020) Grant agreement n. 663474

### **Organised session 5: Models of safeguarding**

**Session organiser: Martin Stevens**

*King's College London*

#### **Session overview**

Local councils in England now have a statutory duty, under the Care Act 2014, to make enquiries when a concern is raised about potential abuse or neglect of adults with care and support needs and to establish multi-agency adult safeguarding procedures. However there is no prescription in the legislation about how councils should organise adult safeguarding. This session will report findings from a multi method, multi stage research study, which aimed to identify and explore the implications of different models of adult safeguarding for practice and outcomes in local authorities (and any delegated organisations).

Three papers will be presented in this session. The first will report on a narrative synthesis of the literature, undertaken in the first phase of the study. The review aimed to identify the characteristics of safeguarding practice, which may be important for local authorities to consider when choosing between models of organisation. The degree and implementation of specialism within the organisation of adult safeguarding; decision-making and thresholds for a safeguarding response; and multi-agency working were all identified as important variables. The literature review results were combined with findings from 24 interviews with senior adult safeguarding managers in order to develop a tentative typology of Models of Safeguarding. Further exploration of these models was undertaken in five local councils that had implemented different models of safeguarding, through interviews with managers, social workers, care home managers, and other professionals. The second presentation in the session will describe these models and explore implications for practice. The findings focus on safeguarding as a specialism; safeguarding practice (including multi-agency working, prioritisation, tensions, handover, staff confidence and deskilling); and managing safeguarding. The third presentation will report on findings of a survey of safeguarding workers and an analysis of anonymised and aggregated local safeguarding records and the results of the annual Adult Social Care User Survey in each of the five sites. Tentative implications about outcomes and costs associated with each model will be made.

## **Discussants**

**Katie Graham**, University of York

**Caroline Norrie**, King's College London

**Martin Stevens**, King's College London

## **Presentation 1: Models of safeguarding: identify the characteristics of safeguarding practice**

**Katie Graham**

*University of York*

Co-authors: Caroline Norrie, Martin Stevens, Jo Moriarty, Jill Manthorpe, Shereen Hussein; King's College London

*Objectives:* This paper will explore the organisation of adult safeguarding services in England. It will identify the characteristics of safeguarding practice, which may be important for local authorities to consider when choosing between models of organisation, about which there has been little evidence or policy prescription.

*Methods and data:* The paper presents findings of a narrative synthesis of literature published between January 2000 and September 2013. After development of search terms, five databases were searched and the team undertook hand searching of two journals and accessed a number of reports that were not identified in the electronic searches. In all, the search produced 1753 items, of which 162 were included in the analysis, after screening for relevance.

*Findings:* Many local authorities have developed specialist safeguarding roles, although the implications of specialisation in safeguarding have not been extensively explored. Other variables of importance in developing local safeguarding procedures and practice were identified in the review, including; decision-making and thresholds for safeguarding response; and multi-agency working.

*Policy implications:* There appears to be limited evidence about the outcomes of different ways of organising adult safeguarding, which suggests that further empirical research is needed. However, the review identified important features of safeguarding, which contributed to the development of a typology of different 'models' of safeguarding organisation.

## **Presentation 2: Models of safeguarding: typology and perspectives on implementation**

**Caroline Norrie**

*King's College London*

Co-authors: Martin Stevens, Katie Graham, Jo Moriarty, Shereen Hussein, Jill Manthorpe

*Objectives:* Professionals express divergent views about whether adults at risk are best served by safeguarding work being incorporated into social workers' case work or being undertaken by specialist workers within local area or centralised teams. This paper draws on findings from the final two phases of a three-phase study which aimed to identify a typology of different models of organising adult safeguarding and compare the advantages and disadvantages of these. We used mixed-methods to investigate four different models of organising adult safeguarding which we termed: A) Dispersed-Generic, B) Dispersed-Specialist, C) Partly-Centralised-Specialist and D) Fully-Centralised-Specialist.

*Methods and data:* In each model we analysed staff interviews (n=38), staff survey responses (n=206), feedback interviews (with care home managers, solicitors and Independent Mental Capacity Advocates) (n=28), Abuse of Vulnerable Adults (AVA) Returns, Adult Social Care User Survey Returns (ASCS) and service costs. This paper focuses on qualitative data from staff and feedback interviews and the staff survey.

*Findings:* Our findings focus on safeguarding as a specialism; safeguarding practice (including multi-agency working, prioritisation, tensions, handover, staff confidence and de-skilling); and managing safeguarding. Local Authority (LA) participants described and commented on the advantages and disadvantages of their organisational model. Feedback interviews offered different perspectives on safeguarding services and implications of different models.

*Policy implications:* How adult safeguarding is organised has implications for quality of services for adults at risk and this is of interest to practitioners and policy makers alike.

## **Presentation 3: Models of Safeguarding: costs and outcome**

**Martin Stevens**

Co-authors: Caroline Norrie, Jill Manthorpe, Shereen Hussein, Jo Moriarty, Katie Graham

*Objective:* Adult safeguarding is the subject of increasing attention in England and internationally. The aim of this paper is to explore the implications of the different models of adult safeguarding, explored in the previous papers in this session, in relation to outcomes and costs and to compare the importance of the model of safeguarding with other variables.

*Data and method:* The paper describes the findings of secondary analysis of local data in five councils that have adopted different models of adult safeguarding. Each of these five councils provided anonymous data on safeguarding referrals, which formed their Abuse of Vulnerable Adults (AVA, now known as the Safeguarding Adults Return or SAR) return to the Department of Health, and results of the Adult Social Care Survey (ASCS). The ASCS is run annually by councils and provides a measure of social care outcomes, using the Adult Social Care Outcomes Tool (ASCOT), and a single item indicator of Quality of Life. A tentative analysis of the possible different costs of different models is also presented. Finally the paper includes some of the results of an online survey of safeguarding practitioners undertaken as part of the Models of Safeguarding Study. Associations between the model of safeguarding and other important variables (numbers of referrals, kinds of alleged abuse and characteristics of adults at risk) and outcomes were explored. Associations are also explored between model of safeguarding and social workers' job satisfaction and views about the effectiveness of safeguarding.

*Results:* Dispersed-Specialist sites appeared to have a higher rate of substantiating alleged abuse and lower costs compared with other models. However staff in the two sites operating this model reported lower job satisfaction compared with those in the Dispersed-Generic site. Statistical correlations with outcomes were found with types of victim profiles and the perpetrator/victim relationship.

However, no associations were found between model of safeguarding and social care outcome or quality of life.

*Policy implications:* While further research may be needed to support these findings, the study suggests that decisions about local organisation of safeguarding may be more affected by local organisational contexts than local authority model. This suggests that a nuanced approach is required to policy, to make the most appropriate decisions about safeguarding, in relation to local contexts.

## **Organised session 6:**

### **Developments in ASCOT: reflecting the impact of long term care internationally**

***Session organiser: Ann Netten***

*University of Kent, UK*

#### **Session overview**

Reflecting the impact of long term care is challenging enough, but there are additional complications when we try to identify a consistent approach to different systems internationally. The symposium will describe recent developments in the application of the Adult Social Care Outcome Toolkit (ASCOT), which includes a variety of instruments used to generate a preference based measure of the outcomes of long term care. The session will draw on work on the validity of the 'expected' and 'gain' measures in the toolkit, which attempt to reflect the impact of services in the English context; the application of ASCOT in estimating incremental cost-effectiveness using non-experimental methods and survey data; the challenges presented in translation and application of these approaches in Finland and Austria; and work that is exploring how Dutch members of the general population value poor ASCOT profiles relative to death.

#### **Presentation 1: Exploring the feasibility and validity of a pragmatic approach to estimating the impact of long-term care**

***Juliette Malley, Stacey Rand***

*PSSRU*

Co-authors: Julien Forder, Ann Netten, Ann-Marie Towers

*Objective:* We aim to provide evidence for the feasibility and validity of a pragmatic approach to estimating the impact of long-term care (LTC). It is difficult to evaluate LTC interventions. The available methods all have limitations in terms of their ability to provide unbiased estimates of the true treatment effect, cost of implementation, and application to some evaluation contexts and questions (Heckman and Smith 1995; Byford and Sefton 2003). An alternative approach, described by Mueller et al (2014) as the 'counterfactual self-estimation of program participants' (CSEPP), resolves the evaluation problem by asking individuals receiving an intervention to imagine their own counterfactual in the absence of the intervention, and estimate what their situation would be like in that hypothetical counterfactual situation. We describe an implementation of this approach, developed independently by Netten et al. (2012) as part of the Adult Social Care Outcomes Toolkit (ASCOT), for use in the context of the evaluation of LTC interventions.

*Data and methods:* Our data comes from a survey of 748 adult social care users in 22 administrative areas across England, conducted during 2013 and 2014. The survey used the ASCOT-INT4 interview schedule and also included questions asking respondents and interviewers to reflect on the feasibility of the CSEPP method. These data allow us to: (i) assess the feasibility of the ASCOT CSEPP approach across different groups of social care users; (ii) assess the construct validity of the counterfactual ASCOT score by modelling the score as a function of social care need (using observed needs-related characteristics such as activities of daily living, ADLs); and (iii) assess whether the method produces biased results by comparing the results obtained from the ASCOT CSEPP approach to those obtained using a non-experimental instrumental variables method developed by Forder et al (2014), which we consider to be the best alternative method.

*Results:* In general respondents were able to answer the questions, but a sizeable proportion found it difficult to imagine no other help would step in. Certain groups, such as those with more ADL problems, found the questions and the instruction to assume no help would step in more difficult than others. Analysis of interviewer comments indicates that this may lead to underestimation of quality of life in the counterfactual situation. The ASCOT counterfactual score was associated with needs-related characteristics, providing some evidence for its construct validity. The estimate of the impact of social care is slightly higher than the best available alternative, but the estimates are significantly correlated at 0.45.

*Policy implications:* Compared against the best available alternative approach, this ASCOT CSEPP method provides reasonable estimates of the impact of English social care interventions and is relatively cheap and easy to implement. There may be some bias among people with high needs and more research into sources of bias is needed. Nevertheless, these findings indicate that it may be a useful tool for policy development, enabling researchers to establish quickly and fairly cheaply in small scale studies primary evidence about the potential effectiveness of long-term care interventions.

## **Presentation 2: The impact of community-based long-term care on quality of life: a production function approach**

**Julien Forder**

PSSRU

Co-authors: Florin Vadean (PSSRU, University of Kent) Stacey Rand (PSSRU, University of Kent) Juliette Malley (PSSRU, LSE)

*Objectives:* Little is known about the marginal cost-effectiveness of community-based long-term care (LTC) – or ‘social care’ as it generally known in the UK – especially where effectiveness is rated on ‘utility’ scales. Such information, however, is highly relevant to decision-making about commissioning and resource allocation.

The main aim of this paper was to estimate incremental cost-effectiveness using non-experimental methods and survey data. In particular, the paper sought to estimate the improvement in care-related quality of life (measured in standard utility terms) for an individual that accrues from a small increase in their (cost-weighted) utilisation of community-based LTC. The non-experimental approach was proposed as a practical alternative to experimental evaluation approaches, such as RCTs, which is relevant in this case where services have a self-evident, if non-quantified, effect.

*Methods:* The paper applied a ‘production function’ method. The basis of this method is that we ought to see a correlation between service utilisation rates and people’s quality of life ratings in a survey of service users, and these relationships can be modelled statistically.

We started with a model that accounts for the mutual dependence in utility as between the cared-for person (patient) and any unpaid carer, based on Becker’s model of altruism in the family. This model formed the basis of our empirical specification. We estimated the relationship between social care-related quality of life (SCRQoL) and LTC-service utilisation rates in a survey of patients and carers. Instrumental variable (IV) estimation was used with control on observable confounders to tackle selection issues. Spatial lags in service use across the sample were the main instruments.

*Data:* A specifically-designed survey was undertaken which sampled people using publicly-funded long-term care services provided by local authorities in England. Data were collected from 990 service users and from 387 unpaid carers who helped look after a subset of these care recipients.

*Results:* IV with spatial lags was able to fit reasonable production functions with our survey data. Accordingly, we found that services had statistically-significant marginal effects on care-related quality of life for both cared-for people and unpaid carers. These results were used to calculate incremental cost-effectiveness ratios. We also inferred the strengths and weaknesses of using this approach for evaluation.

*Policy implications:* An important emergent theme for LTC policy is for funding and commissioning to be guided by information on the relative cost-effectiveness of services and support. The imperative is to make the most effective use of constrained public budgets for care. Moreover, effectiveness is best judged in terms of the impact LTC has on people’s lives, including both service users and carers, and not just on how many services are provided. The methods and results of this paper help to inform these policies.



### **Presentation 3: Translation and cross-cultural validation of ASCOT instruments into German and Finnish**

***Ismo Linnosmaa and Birgit Trukeschitz***

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*Aim:* Cross-cultural use of quality-of-life measures have become more common when instruments developed in one country are translated to be used in other countries and cultures. This trend emphasizes the need to establish the cross-cultural equivalence between translated and original questionnaires (Willis 2015). The objective of this study is to explore validity of the Finnish and German translations of the Adult Social Care Outcomes Toolkit (ASCOT) for service users and carers. We translated and tested the interview schedules (INT service user, INT carer) and the self-completion tools (SCT service user, SCT carer). We are primarily interested in the cross-cultural validity and comprehensibility of the translated ASCOT instruments, but our findings from cognitive interviews also contribute to a more general discussion about the applicability of the cross-cultural cognitive interviewing techniques.

*Methods:* The instruments were translated from English into German and Finnish in summer and early autumn 2015 by a translation agency using forward and back translation methods. Cognitive interviews of the instruments were conducted in Austria and Finland in December 2015 and February 2016, respectively, on 10 service users (5 in Austria and 5 in Finland) and 10 carers (5 in Austria and 5 in Finland). Interviewers were natives of Austria and Finland. The think-aloud method with flexible probing techniques were applied in the interviews.

*Findings and conclusions:* According to our preliminary findings, cognitive interviews in Austria and Finland were useful and pointed to phrases and words in the translated instruments where translations were understood differently from the original ASCOT instruments. For example, although ASCOT is a subjective QoL-measure, several Finnish service users interpreted the Finnish translation of the word ‘adequate’ in objective terms. Secondly, some Finnish service users understood the description of the expected situation as the extreme situation with no help at all. Similarly to the Finnish findings, different terms and expressions turned out not to translate easily, such as ‘adequate’ or ‘control over daily life’. On the other hand, we found expressions that may reflect cross-cultural differences in how people talk about their perception of everyday life. Findings of the study will benefit future translations and cross-cultural validation of the ASCOT instruments but also more generally patient-reported outcome measures.

## **Presentation 4: Which ASCOT profiles are considered worse than dead according to the Dutch population?**

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*Objective:* The Adult Social Care Outcomes Toolkit self-completion version (ASCOT SCT4) can be used as a preference-based measure. Country specific preference-based value sets are currently developed. There are a range of techniques available to estimate preference-based values. Dutch preferences for the ASCOT will be elicited using Best-Worst Scaling (BWS). Additionally, the Time Trade Off (TTO) technique can be used to rescale the BWS values to a 0-1 scale making it feasible to calculate social-care Quality Adjusted Life Years (sc-QALYs). TTO values are obtained by asking respondents to trade off quality and length of life. However, it may be unusual for respondents to consider poor quality of life situations as worse than death. Qualitative studies among Dutch respondents show that apart from severe medical conditions there are situations in which persons perceive life is no longer worth living. This may for example be when someone feels disconnected with life, reflected in feelings of loneliness, not mattering, fear of independence and self-estrangement. Some of these situations may be reflected in ASCOT profiles with the lowest levels of quality of life. The aim of this study was to examine how Dutch members of the general population value poor ASCOT profiles relative to death, in order to explore the feasibility of a TTO study with ASCOT profiles.

*Data and methods:* In this pilot study we used the Visual Analogue Scale (VAS) technique to explore Dutch preferences for ASCOT profiles relative to death. Participants were members of the Dutch population, aged 18 years and over. They were asked to rate 25 ASCOT profiles (with a low score based on English preference-based values) and the state of 'being death' on a VAS scale, ranging from worst imaginable quality of life to best imaginable quality of life. Two sets of profiles were randomly distributed to the respondents, resulting in values for 40 ASCOT profiles. Mean scores of the ASCOT profiles were calculated by transforming the scale based on the value of 'being death'. Multilevel regression analysis was used to examine differences in preferences between groups based on gender, age, education, marital status, self-perceived health and self-perceived quality of life.

*Results:* We hypothesize that several ASCOT profiles will be considered worse than death by the Dutch general population, and that persons with a higher age, lower self-perceived health and quality of life are less likely to consider ASCOT profiles worse than death. Results will be available in June/July 2016.

*Implications:* The results of this pilot study will show whether there are ASCOT profiles that are considered worse than death by the Dutch general population. This would contribute to a justification for the use of sc-QALYs and the use of TTO technique to estimate preference based values for the ASCOT SCT-4 in the Netherlands.

## **Organised session 7:**

### **Social investment and long-term care**

***Session organiser: Bernard Casey***

*PSSRU, LSE*

#### **Session overview**

This session is organised around the Horizon 2020 project SPRINT (Social Protection Investment in Long-Term Care) by the principal investigator Bernard Casey, who is on the staff of PSSRU, with contributions from members of the SPRINT consortium, specifically invited outsiders from the scientific and/or policy community, and respondents to a general invitation sent out via the ILPN website.

#### **Paper 1: Applying social investment principles to the provision of long-term care: issues for consideration**

***Bernard Casey***

In 2013, the European Commission (EC) launched its Social Investment Package (SIP). The package had a double objective. First, it constituted an effort to reinvigorate debate about social expenditure, particularly in a time of fiscal austerity. Second, it provided an opportunity to strengthen the social dimension of its Europe2020 strategy – a strategy that, until then, had seemed to concentrate primarily on enhancing ‘economic growth’. The paper will:

- a) provide an understanding of what SI, itself, means – this requiring the many dimensions of the term to be unpacked and the extent to which there is a common understanding of what SI is currently achieving, and what might be achieved, to be made clear;
- b) set the background for an examination of how social cost-benefit analysis might be applied to answer the question: Are there any commonly accepted metrics to reasonably, comprehensively and effectively compare ‘expenditure’ on long-term care services with respect to their quality and social performance?; and
- c) contribute to the discussion about how the principles of SI are or might be used to improve LTC provision in a fashion that is welfare enhancing.

#### **Paper 2: Measuring social investment in LTC: what could be learned from other disciplines?**

***Virginija Poškutė***

*ISM University of Management and Economics, Vilnius, Lithuania*

The concept of social investment is linked with child and youth policy and employment policy. The European Commission has provided a further definition of social investment. According to the EU, social investment are ‘policies designed to strengthen people’s skills and capacities and support them to participate fully in employment and social life’. This includes long term care where it recognises the importance of ‘investing in prevention, rehabilitation, age-friendly environments and more ways of delivering care that are better adjusted to people’s needs and remaining capacities’.

In order to meet the challenges of a growing frail elderly population, there is a need for collaboration between different academic disciplines, including economics, management, public politics, law and sociology, between different public policy actors, especially public, private and non-profit organizations, and between academics and public policy actors. Therefore, the aims of this paper is to analyse possibilities and facilitate the integration of interdisciplinary point of view in order to propose more effective model for stakeholder collaboration that draws form the contribution that can be made by adaptation contemporary best management practises and cost-benefit analysis. Particular attention will be paid to contemporary principles of investment appraisal and the increasing importance attached to double and even triple bottom lines – those measuring ‘social’ and environmental impacts as well as simple financial returns.

### **Paper 3: Benchmarking modes of social investment in Europe: examining forms of long term care in the SHARE database**

***Platon Tinios***

*Piraeus University, Greece and London School of Economics, UK*

Long term care meets similar needs all over the world by using strikingly different means in different contexts. This paper exploits the Survey of Health Ageing and Retirement in Europe (SHARE) of people aged 50+ firstly, to chart the extent of needs using comparable criteria and, secondly, to see the extent to which these needs are still unmet, but also how they are met in different parts of Europe. The focus is thus on two key indicators which affect the ways in which social investment in long term care will operate across Europe. The Care Gap, that is, the extent to which the need for care is not met by any kind of provision, neither formal nor informal and the Care Mix, that is, how the overall provision is split into formal care (professional both public and private), informal (unpaid care by family, friends or neighbours) and a mix of both. Basic findings for the 65+ population are supplemented by an analysis by large age group, gender, and type of household. The 'stylized facts' arising from the analysis can explain differences in the nature of social investment, but also in the identity (and the different criteria used) of those undertaking long term care social investment decisions.

#### **Commentators from practitioner community**

Christina Bolger, Australian Aged Care Quality Agency

Peter Morris, investment consultant, Social and Sustainable Capital (an FCA authorised and regulated fund manager and social enterprise providing finance to charities and social enterprises)

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