## **Devalued later life:**

# Older residents' experiences of risk in a market system Liz Lloyd

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Symposium 1:

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#### Introduction

The purpose of this article is to consider the impact of marketization on the risks faced by older people living in residential care and nursing homes (referred to as 'care homes'). In many western countries, a popular view is that care home residents occupy a precarious position, not only because of their relative poor health and loss of capacity for self-care but also because they are at risk of institutionalisation and, worse still, at greater risk of abuse. Hence the general perception that a care home is a place to be avoided is at all possible. This view is open to question, not least because evidence demonstrates the enormous variety of experiences of life in a care home and because there is growing evidence of the disadvantages faced by older people who choose to remain in their own homes, including loneliness and isolation (Kinsella 2015). The article draws on an analysis of precarity developed by Grenier et al (2017) to argue that in a marketised system of care the risks faced by older people considered to be 'frail' are not confined to those associated with physiological ageing or loss of mental capacity but are contingent on prevailing conditions within the market and, indeed, from the process of marketisation itself. The consequence of this process, it is argued, is that later life has become further devalued.

The article draws on the findings of a research project *Healthy Ageing in Residential Places* (the HARP project), funded by the European Research Area in Ageing 2

(ERA Age 2). This was linked to a larger project *Reimagining Long-Term Residential Care: In International Study of Promising Practices*, funded by the Social Sciences and Humanities Research Council of Canada. Both projects were led from Canada. The participating countries in the HARP project were Canada, Norway, Sweden and the United Kingdom and in the larger project the same countries participated as well as Germany and the United States. The aims of both projects were to identify promising practices in care homes that made the homes good places in which to live and work. The primary questions for the HARP project were:

- 1. What constitutes active, healthy ageing for women and men in residential care facilities?
- 2. What conditions support active, healthy ageing for residents and staff, taking gender, context and individual capacities into account in providing long-term residential care?

The rational for the research was a shared concern about the negative impact of community care policies on the place of care homes and on the people within them as well as shared interest in the relationship between the working conditions and living conditions in care homes. Key to the analysis of all of these issues was a focus on the policy contexts in each of the jurisdictions.

#### Literature review

## Precarious life

A range of gerontologists and others have argued that the old age needs to be understood by reference inherent vulnerability of the human condition. In doing so the focus is broadened from that which separates old age from the rest of the life course and emphasises precariousness and dependency as pertaining to older people *per se.* Turner (1993), for example makes the point that all individuals may be viewed as ontologically frail, *in part* through the effects of ageing and decay. Similarly, Butler (2006, 2009) points to inherent vulnerabilities in the human condition but argues that we need to look beyond such inherent properties to understand how the vulnerabilities faced by many people are contingent on particular economic and

political contexts. Care ethicists, such as Tronto (1993) and Barnes (2012) also point to the ways in which economic, political and policy contexts affect conditions of dependency and relationships of care. Standing (2010), emphasises the precarious conditions of work that prevail in globalised economic systems and his analysis is highly relevant to the conditions of work in care homes, which is typically low-paid and insecure, often with poor working conditions. Butler (2006) also emphasises how cultural frameworks shape our thinking about what counts as a valued life. The classification and 'othering' of particular groups as inherently vulnerable create the conditions for devaluation. These insights are particularly illuminating when applied to an examination of risks for residents in a care home. While risks or insecurities are part of the human experience they are shown in stark relief in old age when human dependency on others for support and care in everyday life necessitates a move to a care home. When this move is made in a marketized system of care there are particular risks involved, as discussed.

#### Risks in care homes

Basic requirements for the protection of residents and staff in care homes apply irrespective of systems of financing or policy frameworks. Many of these requirements are indistinguishable from health and safety systems that apply in most contexts and are concerned with making a building habitable. These include sufficient space and light, clean air, sanitation and appropriate temperature as well as preventive emergency procedures. Others are more specific to the needs of residents who may have mobility problems, poor health or cognitive impairment. The minimisation of risks is a core feature of the design of care homes. Design should also maximise the potential for activity and freedom of movement. The approach to care in a care home should minimise the likelihood of pressure ulcers, falls and infections. Procedures that minimise the likelihood of ill-treatment of residents by other residents and staff are also required. In short, a basic necessity is recognition of the vulnerabilities of residents and a legal and policy framework that ensures that appropriate systems and procedures are in place. At the same time, there is a positive side to risk and inspection and regulatory regimes need to be alert to the possibility that over protective regimes carry risks also. For example, if a care home discourages residents from activities that increase the risk of falls, they need also to

consider the risks associated with a lack of activity. This awareness is not always built into inspection regimes (Choiniere et al 2016).

The right to take risks, to explore and engage with the world around enhances the quality of life and, arguably, is at the heart of individual autonomy, citizenship and human rights. Relatives and residents value nursing home environments that encourage a degree of individual risk-taking, which can be understood as a counterbalance to the risk of institutionalisation. Research by Chalfont and Rodiek (2005), for example, identified how relatives valued care home regimes that promoted curiosity and engagement in everyday activities. 'Person-centred care' is essential but can be over-protective, concerned only with the personal safety of each individual resident rather than with promoting their more general welfare as human beings. In the UK a disparaging term sometimes used to describe care homes is 'God's waiting room', a term that suggests that residents in are in a twilight zone having already lived their lives but not yet dead. The right to take risks, on the other hand, points to the fact that residents are still living their lives and therefore, still open to learning and new experiences. In this sense, the right to take risks contributes to a continuing sense of self (Lloyd et al 2014). Opportunities to learn and take risks require recognition of the potential of risk-taking to enhance quality of life and awareness of the dangers of an over-emphasis on risk avoidance.

Staff in care homes therefore face a continuous tension between, on the one hand, the promotion of personal autonomy, control and risk-taking for residents and on the other hand, responsibility for the safety of residents as well as accountability to families and other stakeholders. These points have been explored at length by, for example, Evans et al (2016), Innes et al (2011) and Peace et al (1997). Understanding the positive side of risk-taking needs to be central to the culture of care in any care home and if front-line staff are to be truly able to promote positive risk-taking this awareness needs to be shared by managers and owners as well as by relatives and volunteers. There is copious evidence that residents and relatives place great emphasis on staff attitudes and behaviour as essential to a good quality of life in a care home (see for example Popham and Orrell, 2011). For staff to meet the expectations of resident and relatives, a supportive managerial system is essential. As argued above, however, the wider contexts in which care homes

operate also play a crucial role in shaping experiences of vulnerabilities. A key question, therefore concerns the impact of legal, policy, regulatory and organisational contexts on the tension between the protection of vulnerable residents and the promotion of positive risk-taking and the impact of the marketization process on this tension. Evans et al (*op cit*) focused on care home managers' attitudes to the balance between safety and risk and identified no difference between the type of care home ownership on this but they suggest more work is needed on this as their sample was small.

## Markets in long-term residential care

The market model has redefined care as a commodity to be commissioned by municipal authorities, or purchased by individual consumers from a range of independent providers, with individual need being the basis of a transaction and a contract. Claims for markets in social care have generally revolved around the relationship between cost and quality. Within contemporary political and economic discourse, markets are still considered to be the best way of driving down costs and driving up quality.

At the same time, the introduction of markets has coincided with campaigns by disabled people against the kind of institutionalisation that was characteristic of many state-run care homes in the mid to late twentieth century. Policy discourses of individualisation, consumer choice and the 'tailor-made' approach to care stress that these are an alternative to the 'one size fits all' approach associated with residential institutions. The demands of campaigners for greater voice in the development and running of services are still ongoing as the marketisation process offered a consumerist version of choice and control through the right of exit. In the UK, campaigns have evolved into a 'personalisation agenda', which continues to call for the provision of individualised, non-institutionalised services that support individuals according to their specific needs and involves them in actively assessing those needs. The personalisation agenda assumes that people can be responsible for their own decisions about what they need but also that they should have information and support to enable them to do so (Carr and Ditrich 2008). In this sense, the personalisation agenda shares with the consumerist agenda the vision of an older

person in the care system as a well-informed individual who is capable of exercising choice within the market. Several critiques of this vision have been developed. Lloyd et al (2013), for example, point out that older people's decisions about moving to a care home are often made when they are in a state of crisis. Moreover, as discussed below, the functioning of the market in the UK has not been conducive to the promotion of choice and control because there has been insufficient capacity within the care system. Evidently, the security and quality of services in a marketised system depends in part on how well the competition is working, as argued by Forder and Allen (2011). To have choice there must be sufficient providers and to have sufficient providers there must be a conducive policy regime.

The claim that a marketised system drives up quality is open to question, given the evidence on standards of care in different jurisdictions. Ronald et al (2016) argue that care quality is a multidimensional concept with no gold standard against which the quality of a specific home can be measured. They point to the greater likelihood of inferior care in care homes in the for-profit sector, when factors such as staffing levels, the amount of time devoted to the care of individual residents as well as the incidence of pressure ulcers are taken into account.

## Methodology and data

The methods used in the HARP and Reimagining Long-term Residential Care research projects included comparative analysis of the systems of financing and accountability of care home systems in the participating countries, the systems of staffing the terms and conditions of work that applied as well as the approaches to care. This included extensive analysis of secondary data, including policy documents, industry reports, regulator reports and audits of services. Primary research took the form of rapid, site-switching ethnography. In each of the participating countries a team of researchers spent a week in selected care homes working in pairs of 'home' and 'foreign' researchers to interview residents, relatives, managers, a range of staff and volunteers as well as to conduct observations of daily life in the home throughout the day and evening. In total, 14 sites visited for a period of a week and an additional 11 sites were visited for 1 day 'flash' visits. More than 500 interviews were conducted and researchers' field notes amounted to more than

1500 pages (see <a href="http://reltc.apps01.yorku.ca">http://reltc.apps01.yorku.ca</a>). It is important in this discussion to bear in mind that the care homes observed were selected because they had a reputation for being 'good' places, as defined by local experts. Thus, it might be expected that staff would have developed effective ways of managing the tension between protection and risk in the daily routines of residents.

## **Findings**

A full discussion of findings relevant to the question of risk management is beyond the scope of this article. The discussion below focuses on the evidence we observed and gathered in interviews related to the tension between protection and risk. It includes findings that demonstrate wide differences in attitudes to risk within as well as between the jurisdictions covered and within as well as between the for-profit and not-for profit care homes that were observed. There were few examples of seriously neglectful behaviour, although in one home in the UK the death of a resident and injury of a staff member occurred when an elevator was left unguarded. The findings from secondary sources related to risks within the market system are drawn from the UK in particular. The constituent countries of the UK differ in some respects, as social care is devolved to the Scottish Parliament and the National Assemblies of Wales and Northern Ireland. The findings here relate primarily to England, although many of the issues covered apply across the whole of the UK.

#### Attitudes to risk

In the literature review above, it was pointed out that activities and routines that involve a degree of risk can have a positive effect on the wellbeing of residents. In our field work we observed several examples of this, such as the use of sharp knives by residents who were engaged in food preparation and the use of tools in gardening and craft work. The tension between protection and risk is ever-present. This was evident even in a home in the UK that was more inclined than many others to facilitate risk-taking for residents. In this home a regular activity was a fitness club, which included the use of 'trampettes' (small trampolines). The physiotherapist who ran the club had great success in encouraging residents to have go on the trampettes, to their evident enjoyment, but he told us that he got frustrated at times

by the tendency of care staff to 'hover' around the residents, urging them to be careful. Clearly the care staff were afraid of the possibility of fall and injuries and that in the event of injury they would be held responsible. This example, highlights the importance of a shared view of the benefits of activities that carry risk and the inclusion of regulators in this shared view.

Knowledge of individual residents' capabilities is a crucial factor in managing the tension between protection and risk. This also involves knowledge of each resident's background and their practical experience of activities. For example, in one home in the UK, a resident with dementia requested to iron her own clothes. A decision whether or not she could involved a lot of discussion between the care home manager, relatives, laundry staff and care staff about whether she should be allowed to go into the laundry room, how hot the iron could be and how much supervision was needed. It was eventually agreed by everyone involved that she could use the iron in the laundry and that she could control the temperature. The manager argued in favour of this and pointed out that she had decades-long experience of ironing. She knew what she was doing and her knowledge included how to avoid getting burnt by an iron. This approach is time consuming and requires sufficient staff to work. It contrasts with that taken in a care home in Canada where for several years an activities co-ordinator had run a very successful gardening club on the roof of the building, which included an annual plant sale - described as the highlight of the year for the gardening club. After a risk assessment by the management the plant sale was stopped because it was considered too risky. There was little room for argument as the decision was made at a high level and imposed from above.

The points of tension can therefore be between staff and between front-line staff and managers. Fear of legal action by families could also deter staff from giving residents the freedom to do things that carried a risk of injury. Decisions on activities cannot be understood as simply arising out of approaches to care *within* care homes, however. They also involve the legal and regulatory regimes and insurance contexts within which care homes operate. Regulators might baulk at practices that enable residents to have easy access to food and drink, particularly where this involves alcohol or hot water. However, we observed homes where residents, including those with dementia, were enabled to continue using lifelong skills, enjoy variety in their daily

routine and maintain a degree of choice and control over their activities. Sometimes, this involved managers providing evidence to the regulators that these practices were worthwhile, and that in practice they were not as risky as might have been assumed.

## Risks to residents in a marketised system

The findings below are drawn from analysis of secondary data. The focus is on the UK, where the provision of care homes is the most marketised of all the jurisdictions in the study. Figures provided by Ronald et al (2016) show that in the UK in 2012, 78% of beds in care homes were in private, for profit ownership, up from 74% in 2007. This compares with 67% of beds in the USA (2008 figures) and 37% in Canada (2011 figures) and 21% in Sweden (2012 figures). The UK has a long tradition of small 'mom and pop' style care homes, with fewer than 10 residents, whose owners might be more accurately described as 'making a living' rather than 'making a profit'. The current trend is towards a reduction in number of these smaller homes and an increase in larger homes operated by large companies.

## Consumer rights of care home residents

A notable development in the UK care home sector is the polarization between self-funders and those who rely on public support. According to the market analysts Laing and Buisson (2012) 41% of residents pay all their own care home costs while another 14% pay a top-up over and above that provided by statutory support. The care homes used primarily by self-funders are generally at the 'higher-end' of the market with relatively affluent residents and the companies that run these are currently flourishing. In contrast, there is a shortage of investment in care homes in less affluent areas and consequently an increasingly diminished choice for older people who rely on state support. Given demographic trends this diminution is a major concern, as continued loss of market capacity will make it harder to find places for older people who do not have the means or the capacity to shop around. As argued above, the claims for choice in a market are open to question when we take into account the crisis situations many older people are in when decisions about

moving to a care home need to be made. The polarization of the market exacerbates the vulnerability of those who do not have the means to pay for their own care.

Another issue to consider in relation to decisions to enter a care home concerns the individualisation of responsibility that exists in a market context. Given the vulnerability of care home residents, we might call into question the ethical basis of the 'buyer beware' principle. A report by Citizens Advice (Citizens Advice 2016) argued that mental and physical health problems are only part of the problems faced by older people. There are also geographical limitations, with some parts of the country being more poorly served than others. The report also points to problems related to timing and the urgency with which decisions must be made. For example, if an older person is entering a care home from hospital, the local (municipal) authorities faced financial penalties if they fail to find a place within a stipulated time. In relation to the consumer power of exit, Citizens Advice point out that few care home residents are likely to switch from one provider to another, especially given that a move can, of itself, carry a risk. Indeed, Greenhalgh and Ogunye (2016) point out that most moves from care homes do not occur out of choice for residents. It is more likely that a resident would be asked to move because their care needs have changed and the home no longer wishes to keep them. It should be noted that in the UK, care home residents have the legal status of 'licensees' which does not give them rights of tenancy.

Moreover, in the UK there are questions about the extent to which individuals are provided with the kind of information that could help them make decisions or understand their rights. In 2005, the Office of Fair Trading reported serious concerns about the lack of information available to the public (OFT 2005). Their research showed gaps in information provided at almost every stage of older people's decision-making process as well as confusion about where to go to get information and advice. The Competition and Markets Authority (the successor organisation to the OFT) is currently conducting a market study of care homes (CMA 2016) which focuses on the question of information. There have been some changes since 2005, including the provision of information packs by local authorities but these are more likely to be made available once a local authority knows an individual who is actively considering a move to a care home. Greenhalgh and Ogunye (2016) identified a lack

of clarity in the information provided about fees and suggest that one reason for this is that in any individual care home a range of fees might be charged. For many families a major concern was whether the resident's money would last long enough for them to stay until they died.

The individualisation of responsibility continues once the move to a care home has been made. Recent 'Mystery Shopper' research by Citizens Advice in over 400 care homes in the UK identified a range of problems. For example, two thirds of the care homes in the study gave less than 4 weeks' notice of fee increases, with one in ten homes giving notice of only 1 week. They also identified instances of hidden or unexpected costs, such as charges to cover the cost of a care worker to accompany a resident for a hospital appointment. A report by Age UK (Lowe 2016) found similar instances. There is some evidence, also, of 'sharp practices'. For example, Greenhalgh and Ogunye (2016) cite examples where a resident's family were presented with an additional bill to cover a change in the resident's care needs. When this was questioned it emerged that there had been no such change. Despite these shortcomings in services, many residents and their families found it hard to complain, in part because of opaque or inadequate complaints procedures. In the report by Greenhalgh and Ogunye (op cit) the main reason why people avoided making a complaint was fear about negative repercussions on the resident. In their scoping statement at the launch of their investigation, the Competition and Markets Authority stated they would address growing concerns relating to:

'the extent to which care home providers are treating their residents fairly and whether they are complying with their consumer law obligations in relation to information provision, contract terms and business practices after the resident has moved in'

(CMA 2016 para 1:3)

## Competition in the market

The process of marketisation has had diverse effects on the way in which care home services are provided. In the UK mergers and acquisitions have led to an increasing share of the market by larger firms and in some areas dominance or monopoly by a

single provider. Forder and Allen (2011) note that the market share of major providers rose from 5% in 1989 to 41.9% in 2010 (a major provider is one that owns three care homes or more). The problems associated with this trend were evident during the collapse of the company Southern Cross in 2008, especially in the areas of England where Southern Cross ran almost all the care homes. However, wider impacts need to be considered, including the reduction of choice for individuals in specific areas and greater difficulty in enforcing standards. Forder and Allen concluded that competition was not working effectively in the UK care home market.

From the providers' perspective, financial problems within the care home market are long standing and stem from what has been described as an unsustainable model of financing. A major issue raised is the level of payments made by local authorities for the residents they sponsor. This involves around 37% of residents in English care homes. Almost ten years of austerity budgets have reduced the capacity of local authorities to increase payments in line with the fees required by care homes. As a result, many care homes maintain a mixture of publicly funded and privately funded places, with self-funding residents paying a higher price than those funded through public funds, effectively providing a subsidy. The findings of Citizens Advice referred to above concerning the lack of information available to older people concerning the fees they are likely to pay are relevant to this point. The fee structures in place in many homes is highly varied as care home owners seek ways of maximising their income through individually negotiated contracts. There are also reductions in services as owners seek ways of reducing costs. One example is to stop providing temporary 'respite' care beds.

A further challenge to the profitability of private sector care homes arose with the introduction of the 'national living wage' for all workers. Front-line staff in care homes are typically at the bottom end of wage scales and there has been a long-standing problem in staff turnover and unfilled vacancies in the sector as a whole. The Independent Living Centre (2017) identified a 24.3% rise in staff turnover in the care workforce in 2016. Problems in recruitment have been solved by the employment of migrant workers. Provider organisations have argued that the increase in staff costs will be the tipping point that causes care home providers to exit the market. An added pressure comes from the prospect of the UK's decision of leave the European

Union. A recent report by the Independent Living Centre (2017) investigated the potential effects of this and concluded that if European migrant care workers lose their right to work as a result of changes in immigration rules it will be almost impossible to close the already sizable social care workforce gap.

In recent years an increasing number of providers have chosen to leave the market choose to leave the market or, in the case of larger firms, to close homes. One of the largest, Four Seasons, closed 41 homes in the year 2015- 6 and plans to close a similar number in 2017. For smaller care homes there is an increased risk of insolvency. There were 380 insolvencies between 2010 and 2016 and the rate at which these occurred increased, so while there were 32 in 2010, there were 34 in first half of 2016. The government response to this growing situation has been to require local authorities to that develop a thorough knowledge of the local market and to be prepared to step in when providers fail. The current policy is that the state needs to assume that there will be provider failure and develop ways of managing this so as to provide protection for individual residents. This policy has been incorporated into the 2014 Care Act that applies in England.

#### Discussion

The points discussed above concerning the level of fees paid for publicly funded care home residents and the cost of staffing raise important questions concerning the relationship between the state, the market and the individual citizen. The assumption that the introduction of the market would have a positive effect on the quality of care is open to question Indeed, Ronald et al (2016) make the pertinent point that when considering the need for policy intervention the precautionary principle should apply. That is, taking account of the vulnerability of care home residents, preventive action should be taken where there is plausible evidence of potential harm. In their view, this evidence already exists and action such as the imposition of mandatory minimum staffing levels and improved financial transparency should be taken.

The expectation that public funds would provide a guaranteed income for private investors was strong, especially in the context of rising numbers of older people in

the population and the continuing steady demand for care home places. This expectation has been undermined by continuing cuts to public spending and the imposition of austerity in services, which have reduced the level of profits to be made and have increased the level of insolvencies. As Hudson (2015) has argued, the risk of market failure is a relatively new policy issue and the government's approach to managing it suggests so far that it will be 'light touch' with due regard to commercial sensitivities. The policy might be regarded as providing a new version of the safety net model which focuses not on vulnerable individuals in the care system but on providers at risk of financial failure.

In 2016, a report by the Association of Directors of Adult Social Services (ADASS) claimed that the continuity of the care market is under threat because of the increased risk of provider failure. Currently, local authorities are grappling with the effects of closures of home care provider agencies as well as care home providers. These policies have created tensions in the relationships between the state and commercial providers with serious effects for older people and their families. The pursuit of policies to reduce the cost of care *and* to promote care markets have generated a crisis that has shown in stark relief the weaknesses of a market model and the precarious conditions it generates for older people, care workers and family carers.

For older individuals, the increased risks associated with the chaotic way in which markets have operated in the UK provide growing evidence that assumptions about people's ability to function as informed consumers in a care market are misplaced. The closure of care homes has reduced their choice and increased the likelihood that they will be unable to find a place that suits them or that they can afford. Moreover, they continue to face financial risks while in care homes because of practices of imposing unexpected costs as well as health risks associated with unplanned moves when care homes close. These risks are spread unevenly affecting people differently according to their capital resources and incomes as well as their particular needs (there are heightened risks for people with advanced dementia, for example) and their geographical location.

These increased risks reinforce the argument raised at the beginning of this article concerning the way that individual vulnerabilities in old age are a function of political and economic contexts as well as the effects of ageing and ill health. A focus on risk in the context of marketisation highlights the inadequacy of the model of the individual consumer citizen. The citizen status of older care home residents is deeply undermined by the austerity agenda, in which finding ways to cut the cost of care overrides all other concerns. This has repercussions for their ability to engage in meaningful activities and to take risks in their everyday lives because in a poorly funded care home cutting costs is likely to lead to a reduction in activities, a more risk averse regime of care and a less personalised service.

#### Conclusion

The marketisation of care homes in the UK has not produced a higher quality of service for residents. While the experience and expertise of staff and managers can promote positive risk-taking and reduce hazards in care homes their practice cannot be understood in isolation from the context in which care homes operate. The marketised system in the UK has failed to promote a high quality system of residential and nursing home care and has generated new forms of risk for older people.

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