Ageing and agency: The contested gerontological landscape of control, security and independence and the need for ongoing care and support.

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What good ageing looks like has been subject to great debate. Over time this debate has involved researchers developing a complex series of models that have evolved to include both physical, social, emotional and environmental factors (Sandra Torres, 1999; Bowling and Iliffe, 2006; Baltes and Carstensen, 2008; Doyle *et al.*, 2010; Potempa *et al.*, 2010). Whilst some authors have argued that life satisfaction increases with age (Healy, 2004) others have reported is decreases (Gwozdz and Sousa-Poza, 2009). However, one commonality across discussions of successful ageing, ageing well, healthy ageing and life satisfaction, is the role of the individual and the value that is placed on independence in later life (Sin, 2007).

The Birmingham Policy Commission explored through evidence gathering and from the literature on successful and healthy ageing, the idea of independence and what that might look like in a 21st Century context in Birmingham. Both the evidence and the literature pointed to several key themes that this submission will look at in relation to the work of the Commission. These themes included: and independence, agency and choice; Independence and the relationship to health and wellbeing; and the role of the family, the individual and the state.

Independence, agency and choice

These two concepts have really become synonymous with health and social care reform in the UK over the last two decades. Under the aegis of these ideals, substantive change has been wrought in both the administration and funding arrangements for health and social care. The explicit focus of the work of the Commission was to explore healthy ageing, and as part of the evidence gathering there were examples of older people's complex understanding of choice and change in relation to their health and social care needs:

> *"I don't want to go into a nursing home ever. I want to live in my own home until I go to my rose garden"* (UK Caribbean Seniors)

> *"Change in general is very challenging for many people, and when it is in the form of aging it is very easy to become anxious and worried"* (Halesowen Asian Elderly Association)

> *"Change is common element of life and we need to accept change with the right help and support"* (Halesowen Asian Elderly Association)

> *"So long as I could be with others, and can take care of myself than being old in Birmingham is not a problem"* (Clifton Road Mosque Ladies Group)

Phillipson and Powell (2004) recognise that "ageing experiences are themselves hugely and increasingly diverse" and this was supported by the evidence gathering of the Commission. It was seen that ageing was a personal and individual process that conversely happens to everybody. Academic researchers find the notion of choice and ageing as often difficult ones in relation to other

important concepts such as agency. Biggs (2004) looked a choice and agency, and mused that "one of the most important challenges arising from an aging identity is the emerging recognition of one's inability to choose not to grow old. Agency, therefore takes on a deeper aspect, in so far as it is associated with increased personal integration and the ability to express oneself in circumstances not of one's own choosing, both of which occur as part of the process of adult aging. Agency in later life has to take a position in relation to bodily challenges, social prejudice and the fact that life is finite" (Biggs, 2004: 138).

The Commission heard evidence from [Ayesha Janjua](#) of the Office for Public Management (hereafter OPM) who described their findings in relation to the wants and needs of older people as being strongly linked to this theme. OPM found that older people wanted independence and to feel as though they were making a contribution, but that there was a clear role for the state and often a role for the private sector i.e. bus schemes run by local supermarkets to enable transport for grocery shopping.

The importance attached to being able to adapt to new situations and embrace ageing as a process that is inevitable but one of change is bound up in ideas about identity, and individual choice. Biggs (2004) further elaborated his conceptualization of agency in relation to ageing through his analysis of Rowe and Kahn (1987)and Baltes *et al.*'s (1990) models of successful ageing stating that "a common threat that exists between the three models for 'success' in aging outlined above lies in the sense of continuity, or the need to maintain continuity of identity for as long as is possible" (Biggs, 2004: 142). This has particular salience for the personalisation agenda in the UK. Personalisation is defined by the Social Care Institute for Excellence as: "recognising people as individuals who have strengths and preferences and putting them at the centre of their own care and support. The traditional service led approach has often meant that people have not been able to shape the kind of support they need, or receive the right kind of help. Personalised approaches such as self-directed support and personal budgets involve enabling people to identify their own needs and make choices about how and when they are supported to live their lives. People need access to information, advocacy and advice so they can make informed decisions. Personalisation is also about making sure there is an integrated, community-based approach for everyone" (Carr, 2008).

Personalisation has (as was intended) materially affected people's experiences of ageing, however the evidence base for improved care or access to services has proven inconclusive (Carr and Robbins, 2009). Further, in their work Carr and Robbins found that there were gaps where it was found that for some older people and "in addition to those eligible for state or local authority funding, there are a significant number of people in England and Wales (particularly older people) who do not meet social care eligibility criteria but who nonetheless need care and support. These people have been recognised as being 'lost to the system'" (Carr and Robbins, 2009). According to a recent Age UK blog:

> "'most older people eligible for a personal budget – about 85% – end up with one managed by the local authority'. Which would be alright, except that this usually means little effective choice or control. Some people don't even know they're on a personal budget. In many places they're restricted to having services from a very short list of 'preferred providers'. Selected by a process that's almost entirely focussed on keeping the price down, there's little or no difference between the preferred providers. 'Choice' becomes a mockery", (Age UK, 2013b).

Clearly there is dissatisfaction with the way in which choices are being offered and Age UK argue that "the solution isn't to force older people to accept direct payments they don't want. The solution is to ensure that managed budgets offer the same level of choice and control as direct payments" (Age UK, 2013b).

Personalisation, could in principle offer huge opportunity for ageing populations, however only if the policy focus can embrace all facets of ageing as a process and not just one. Autonomy and choice are only part of a very complicated picture of what helps people to age well. One of the themes apparent in the literature in relation to changing perceptions of ageing, is the emphasis on the need to involve people in decision making about their ageing and planning for ageing well, and also in research, particularly associated with issues such as rurality and dementia (Ellins, 2009; Milne *et al.*, 2007; Lui *et al.*, 2009; Walker, 2007). This reinforces the work of other areas of the Policy Commission where findings related to not only the importance of independence and autonomy over decision making, but also the need to feel connected to communities.

Independence is a recurrent theme identified as vital in helping people to age successfully and with dignity (Sin, 2007; Age UK, 2013a; Age Concern, 2010). These concepts of freedom versus control; of autonomy and respect; and of dignity and choice; and of community and connectedness, do not chime well with notions of need for support and enablement, and the highly individualized current provisions of care. However, there is broad agreement in healthy ageing literature, that people being enabled to live independently and being facilitated to build or maintain resilience is an important feature of any policy in relation to older persons. Whilst there is growing recognition that ageing can be successfully achieved, the majority of genrontological literature still focuses on the problems associated with poor health and ageing. Resilience and ageing can also have negative connotations, and there is tension with how people perceive themselves successful ageing outside the understood medical model (Bowling, 2005).

Work on resilience in health contexts includes that of Wiles *et al.* (2012), who show that resilience is embedded in social and physical contexts and inextricably linked to individuals relationships with others. This supports findings from other work of the Policy Commission around the importance of community and feeling connected to place and space.

Independence and the relationship to health and wellbeing

The relationship between successful and healthy ageing and health is not as straightforward a relationship as the inclusion of 'healthy' as adjunct to ageing implies. As Age UK explain, "ageing is not a matter of chronology but restricted activity. Most people begin to feel 'old' as a result of illness or disability. Rather than assuming that this is inevitable, because people are old, or permanent, actions are needed fast to restore function (physical and mental) or to re-skill by finding new ways to do things, such as opening jars. The evidence is clear, even among frail older people in their 90s, mild exercise can have beneficial effects both physically and mentally" (Age UK, 2013a). This relationship an individual has to their health and the impact it has on their wellbeing was supported by findings from the evidence gathering process for the Policy Commission:

> *"In my case I feel as if I have lost my identity, I suffer with lot of joint pains and unable to sleep at night so always feeling tired, general weakness in terms of physically and emotionally"* (Arabic Women's Awareness Group)

> *"I have not aged the way that I wanted to and that is because unfortunately, I had a stroke at a young age way before I was due to retire. This left me with disability and felt I aged before my time. Most important thing to me is being independent"* (UK Caribbean Seniors)

> *"Good health means that you could manage on your own. There are many aspects to ageing well. Physically, mentally and spiritually is so important. I think if you keep fit than you will feel happier in yourself and feel and look younger"* (Halesowen Asian Elderly Association)

Physical health as linked to independence was also something that was widely discussed by participants in the focus groups. However there were different perceptions and often different cultural perceptions in relation to the support needs when older; who should offer support; and how independence was understood differently by different people. For some it was the ability to do things as before, for others it was having control over ones affairs, and for others it was strongly associated with good health and an active lifestyle.

> *"When we become old we are like children, so you need your children to look after you. This is why children are important and you have to raise them properly so they grow up to respect you. But things are now changing with young people, and some young people do not want to live with their elders"* (Arabic Women's Awareness Group)

> *"But she was still climbing an apple tree when she was 79. She'd been an independent lady for years"* (Halesowen and Dudley Elders Group)

> *"Being independent is for me really the most important thing, and being in-charge of your life, without depending on others is vital"* (UK Caribbean Seniors)

Irrespective however, all participants valued their own notions of independence. **Further research needs to be done to understand exactly what independence means for different people and different cultures, and how it is understood and therefore replicable in terms of successful and healthy ageing.**

Mental health and wellbeing were described as also being important in relation to how people understood processes of healthy ageing. This issues raised by participants in focus groups around these issues supported broad findings from the UK The UK Inquiry into Mental Health and Well-being in Later Life, which "identified five themes that older people said were important to their mental health and well-being: Discrimination – Age discrimination, both in service provision and in wider society, was seen as the biggest barrier to mental health and well-being in later life; Participation – Older people need to be able to participate in economic, civic, social, cultural and political life; Relationships – Having friends, family and neighbours are all important, as is feeling part of a wider community; Health – Good physical and mental health and having access to high-quality care services is key; Income – Older people say that they want to have enough money, but view the ability to provide for others and feel part of society as more important" (Age UK, 2010)

The Commission also found that there are specific groups whom are more vulnerable during the ageing process due to increased isolation or financial vulnerability. One of the recurrent themes from some participants in the process was the vulnerability of those who are or have been carers as they age, and in particular, the repercussions when the person for whom they have been caring dies.

> *"No doubt there seems to be an increased sensitivity to the ageing process, people tend to struggle when it comes to care for an aging family member or loved one. Often makes you think about your own future, if there will be someone who will provide you with a right care and support?"* (Halesowen Asian Elderly Association)

> *"My family are really important to me, but so is my independence. I looked after my wife for many years as she was disabled and sadly she died few years ago. I really thought that how am I going to cope, and I felt really isolated at the time. But soon after I was introduced to this group, and do you know something, I look forward to every Monday and Tuesday when I could come here and in fact this group is like my family now. So having interest and a good network really helps to break the isolation. I too live on my own, but I am so happy as I don't feel lonely"* (Halesowen Asian Elderly Association)

There is clearly a difficulty in determining what constitutes successful ageing within contemporary understanding and this links to how health and ageing are often conflated in public perception and in policy and planning. These discussions support Biggs' (2004) research that showed "when interrogated further, these assumptions are often based on the absence of something else, mostly illness or infirmity; or in comparison to one's peers; or to social expectations, carving the lifecourse up into age-specific tasks...this makes agency very difficult to articulate, other than in terms of what one should not be doing" (Biggs, 2004: 139). From developing understandings of healthy ageing in relation to independence and the inherent tension in doing this when people naturally compare or require support or enablement to become independent, the work of the Commission has been able to show that just stating that people need independence without a deeper more nuanced understanding of what that means is fatuous. The concept is differently understood by different people and importantly, the work of the Commission it is clear that **particular attention needs to be paid to those older people who are or who have formerly been carers in relation to their support needs for successful ageing. These needs are distinctive and potentially differ from the general ageing population. Further research is needed into the nature and understanding of role, agency, and choice, and also the process of successful ageing for older carers.**

The role of the family, the individual and the state:

Independence and choice however are not conceptualised exclusively in relation to health. There was a great deal of debate (both academically) but also in the focus groups, about the role of the family in relation to the individual and the role of the state. There is an academic understanding that ageing links to processes of state and the services offered or not to people. Phillipson and Powell (2004) argue that "growing old is itself becoming a more social, reflexive and managed process, notably in the relationship between the individual, the state and a range of public as well as private services: this involves the 'political domain'" (Phillipson and Powell, 2004: 22). The role of the individual and the role of the state in healthy ageing are contested political ideas, which appeared within the dialogue that took place in the focus groups:

> *"I think we're back to this thing with the couples, you know, when you are a couple I really think that the one would look after the other, I don't think the state needs to interfere at all. Unless it's something medical that you can't do"* (Halesowen and Dudley Elders Group)

> *"I think it's the other way around, I think the grandparents feel obliged to look after the grandchildren"* (Halesowen and Dudley Elders Group)

> *"My youngest son lives over the road which is absolutely marvellous, I thought he was going to move a few weeks back, I nearly had a coronary, because I love my daughter-in-law to bits, she's great. And they look after us, like I had that fall last week they were straight over weren't they, and they cleared the snow and everything without being asked. But I do help"* (Halesowen and Dudley Elders Group)

> *"I know with many Asian families the seniors live with their family, but I tell you that they have no life because they feel it is their responsibility to look after us, but the young people are too busy trying to cope with their jobs and their young family etc. so how can they look after us properly. I think being independent is really important in your old age, but you do need money to live life to the full and knowing where to go to seek help is really beneficial too"* (Halesowen Asian Elderly Association)

"In an ideal world we should all think that it is down to us as individual to plan for the future, but it is not that easy when you are busy working and raising family. So the state does have some responsibility in supporting people to age well" (UK Caribbean Seniors)

"I think it should be individual + their family" (UK Caribbean Seniors)

There are difficult, almost teleological questions being asked and investigated by the participants in these focus groups. However across the three areas discussed in this finding of the Commission here, we see that there is some similarity within the difference and patterns of what people feel or academics understand to be important emerging. Are these things so very different, or do people want independence but to be cared about and for? This is a very natural and understandable approach to independence but it is the ultimate challenge for healthy ageing policy of the 21st century, to see if it can support and sustain both things in one relationship.

Part of the academic debate around ageing it has been argued, stems from notions of risk. Phillipson and Powell (2004) look at risk and notions of agency in the UK, through analysis of "historical narratives of social welfare, which positioned older people as 'dependent' individuals and groups in society" (Phillipson and Powell, 2004: 17). In their work they look at how "risk is shrouded in historical and contemporary political debate about whose 'role' and 'responsibility' it is for welfare provision in society – does it reside with the state or the individual? Or some combination of the state, the family and the individual older person?" (Phillipson and Powell, 2004: 17).

The Commission looked at what healthy ageing meant in relation to some of these ideas, and an incidental finding of the Commission through evidence gathering is that people feel that the state should and does have some responsibility for ensuring the optimisation of that process. Whilst many people accepted that they needed to make provision and plan, there were many for whom adverse life events had derailed those plans. There were others who had existed working in poor conditions and never having recourse to put money aside for their old age. There was a sense that in some part, the responsibility and accountability of state was related to their notions of connectedness, that there was an understanding of being part of a wider community of citizens, and an idea that whilst sometimes dissatisfying, that relationship with state as well as family and as an individual experiencing ageing was important. The challenge for policy makers exploring healthy ageing in the 21st century is as Powell and Gilbert so poetically put it, is to "develop approaches that maximize potential and provide sustainable options for people to meet their health and social care needs while also avoiding recreating deserts of marginalized people" (Powell and Gilbert, 2011: 85).

The Commission has found: Older people want control and independence but they also want security and some need care and support; these desires can be in tension. We need a greater understanding of older people's views on how to reconcile their needs and desires in relation to control, independence and security.

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