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People with learning disabilities and 'active ageing'

Accessible summary

- People are living longer and policy makers are talking about 'active ageing'.
- Active ageing can mean older people being still physically active, still working and still being involved in their local communities.
- Most policy makers don't talk about people with learning disabilities and active ageing, but this paper does.
- We also say that people with learning disabilities should be involved in inclusive active ageing research.

Summary

People (with and without learning disabilities) are living longer. Demographic ageing creates challenges and the leading policy response to these challenges is 'active ageing'. 'Active' does not just refer to the ability to be physically and economically active, but also includes ongoing social and civic engagement in the communities of which older people are a part. Though intended to apply to all citizens, discussions surrounding 'active ageing' have all but ignored the experiences of older people with learning disabilities. This paper explores the focus of active ageing discussions in relation to the general population drawing comparisons with the experiences of older people with learning disabilities. The paper concludes by arguing for inclusive research in active ageing which takes account of the concerns and interests of older people with learning disabilities.

Keywords

Active Ageing, civic engagement, employment, learning disabilities, life course, older people

Introduction

This paper discusses 'active ageing' and older people with learning disabilities. People (with and without learning disabilities) are living longer and active ageing is the leading policy response to the demographic challenges of ageing populations (Author). 'Active' refers to 'continuing participation in social, economic, cultural, spiritual and civic affairs, not just the ability to be physically active or to participate in the labour force' (World Health Organisation (WHO) 2002, p.12). There has been considerable discussion of active ageing in relation to the general population but the experiences of older people with learning disabilities appear largely to be missing from these broader debates. Two papers (Buys et al. 2008; 2012) do however engage directly with the WHO concept of active ageing in research with people with learning disabilities. Our aim in this paper however, is to draw together broader policy discussions of active ageing with the experiences of older people with learning disabilities.

Initially, the paper outlines the emergence of the active ageing framework and how it has been applied in policy developments. In relation to the general population, policy discourses on active ageing emphasise older people's ongoing contributions to the economy through extending their working lives. There are also discussions of older people's active civic engagement in the societies of which they are a part, and moves towards a life-course approach to active ageing which focuses on older people's employment history and the preparations they make for older age *throughout their lifespan*. We discuss each of these areas in relation to the general population before going on to extend discussion to older people with learning disabilities, arguing that their experiences are largely missing from broader policy discussions of active ageing. The paper concludes by arguing for an understanding of active ageing which is inclusive of the experiences and perspectives of older people with learning disabilities.

Active ageing and its emergence

In recent years, there has been an increase in longevity and an expansion in the proportion of older people in the UK. In 2012, the period of life expectancy at birth in the UK was 79.0 years for males and 82.7 years for females representing an 8% increase for men and an almost 6% increase for women since 1992 (ONS 2014). While this is a cause for celebration it also presents challenges. The main policy response in the UK and Europe has been the 'active ageing' framework. This focuses on maximizing health, participation, and security in older age (WHO 2002). Although there has been considerable debate about the ways in which active ageing can be operationalised to reach all citizens (Boudiny 2013), it is apparent that the implications of active ageing for different groups have received insufficient attention; this includes people with learning disabilities, the focus of this article.

Active ageing represents a vision in which facilitating the rights of older people will enable the expanding population to remain healthy (reducing health and social care costs), stay in employment longer (decreasing pension costs), whilst also fully participating in community and political processes (Author). The concept of active ageing has achieved widespread currency only in the past 10 years, especially in

Europe, due largely to the efforts of the World Health Organisation (WHO). There is however, widespread disagreement about its precise meaning and it has been suggested that is commonly used to mean 'all things to all people' (Walker& Maltby 2012). The history of active ageing has been traced from its emergence in the United States in the 1960s as the antithesis of the theory of disengagement. The theory of disengagement viewed old age as a time of inevitable withdrawal from existing roles. In this period the key to 'successful ageing' (Pfeiffer 1974), a term which has dominated in the USA, was perceived to be the continuation of activity in older age (especially associated with employment) and retention of values typically associated with middle age. As such, preventing the inception of old age was central if successful ageing was to be achieved. However, this approach was criticised for being predicated on reductionist aims, placing unrealistic demands on individuals in older age to maintain levels of activity which many older people were unable to achieve as a result of functional restrictions. It was seen as overly optimistic and individualistic in approach, failing to recognise the heterogeneous nature of older age (Zrinščak & Lawrence 2014). In the USA in the 1980s these debates resurfaced in the guise of 'productive ageing' which was, ultimately, too narrowly focussed on older people's paid employment (Clarke & Warren 2007).

In the 1990s a concept of active ageing began to develop which emphasized the link between health and activity (WHO 1994). The resulting 'Active Ageing Policy Framework' (WHO 2002, p.12) defines active ageing as 'the process of optimizing opportunities for health, participation and security in order to enhance quality of life as people age'. In addition to a focus on employment and productivity it also emphasised health and the involvement of older people as full citizens. 'Active' refers to 'continuing participation in social, economic, cultural, spiritual and civic affairs, not just the ability to be physically active or to participate in the labour force' (WHO 2002, p.12). Active ageing is about maximising paid and unpaid activities related to employment, politics, education, the arts and religion. It also asserts that older people not in paid employment and those who are ill or live with disabilities can and do remain active contributors to their families, communities and nations. The WHO also recognised the importance of experiences earlier in the life course for determining well-being in later life, as well as the social nature of ageing, in that the process does not occur in isolation (Hamblin 2013).

Active ageing emerged at a period when the issue of 'global greying' led to the dismantling of traditional conceptions of the life course which equated the oldest phase of life with inactivity (Boudiny & Mortelmans 2011). For instance, the abolition of the default retirement age of 65 in 2012 in the UK has led to a blurring of age related retirement (Author). Older people have played an important role in direct action in the form of protests against cuts in pensions, health and social services (Author). They are increasingly found on advisory boards, and non-governmental organizations (NGOs) have also often supported the activities of older people engaged in the politics of ageing (Walker & Naegele 1999). Active social engagement, making connections with people and the community, such as being an active participant in clubs, religious organisations or volunteer work, can enhance well-being (Harmell *et al*. 2014). There has also been a greater emphasis on those activities to ensure the protection, dignity and care of older people and their physical, social and financial needs and rights (Stenner *et al*. 2011).

In essence, the concept of active ageing combines the core elements of productive ageing with an emphasis on quality of life and participation (Walker 2002). It represents a departure from notions of ageing in purely economic terms toward a more holistic approach (Author; Walker 2002). Active ageing may be seen as part of a 'new paradigm' of ageing which refutes the 'decline and loss paradigm' associated with the consequences of physical decrescence (Townsend 2007), and also emphasizes the roles older people play in society. It is important that being active as opposed to passive involves living by one's own rules rather than being 'normalized' by others in order to avoid denunciation.

Policy developments

The evolution of a policy discourse on active ageing has largely comprised of two contrasting models. On the one hand there has been a narrow economic or productivist approach, which focuses predominantly on employment and the extension of working life. As such, population ageing may be seen as 'a tremendous opportunity if longer and healthier lives are matched by longer working lives' (OECD 2006, p.3). On the other hand, there is also a more comprehensive and holistic approach to active ageing supported by the WHO and the United Nations, as well as some parts of the European Commission (Author). For instance the UN (2002; Article 10) stated that older people's potential offers 'a powerful basis for future development' as their skills, experience and wisdom have a lot to offer to society as a whole.

However, in practice there has been an emphasis upon individual responsibility, as opposed to developing social and economic strategies to optimise individual opportunities (Lloyd *et al*. 2014). Despite the potential to create a more expansive approach to ageing, the associated emerging policy has given prominence to productivity (Walker 2009). For instance, the European Commission stated that Member States should develop active ageing policies which provide incentives for older people to maintain their skills and remain active in the labour market (2001, p.50).

The European Commission's (2009) 'Ageing Report', outlined a similar discourse which advocated that it is necessary to better incentivise people to remain in the labour market by raising the retirement age and restricting access to early retirement schemes. This productivist and rather utilitarian vision advocates the need for older workers to be 'activated' to enhance growth in the economy (Author). This approach excludes those not in paid employment, and the valuable contributions they make risk being ignored, reducing the discourse to its precursor 'productive ageing' (Boudiny 2013). In the UK, policy discourse has largely conformed to this approach by encouraging delayed retirement in a number of ways including increases in the age at which the state pension will be received and the abolition of the default retirement age. In addition, tighter eligibility for disability benefits (from 1995), in-work benefits and training incentives targeted at unemployed people over the age of 50, such as the New Deal 50 Plus (from 2002), are strategies to encourage older workers' employment (Banks & Smith 2006; Author). Although some policy documents, including those produced by the European Union (EU) consider a wider range of provision, such as lifelong learning, engaging in capacity-enhancing and health promoting activities, and being active after retirement (CEC 2002), the aim is

largely to extend the working lives of older people (Hamblin 2010) and reflect employment targets in relation to older people (Zaidi & Zolyomi 2011); thus excluding the majority of people with learning disabilities who have never been active in the labour market.

People with learning disabilities and social policy

The increased longevity of people with learning disabilities is recent and dramatic. For instance, in the UK, life expectancy for people with Down's syndrome increased from just 9 years in 1929 to almost 60 years in 2010, with the largest increases occurring from the 1970s onwards (Torr *et al*. 2010); a pattern also evident in other developed nations (Bittles and Glasson 2004). There is also evidence of similar recent longevity in people with learning disabilities without Down's syndrome (Coppus 2013). As with the general population, improved nutrition and healthcare have contributed to this increased life expectancy for people with learning disabilities, as has the move away from institutional to community care. It should be noted however that the average life expectancy of people with learning disabilities is still less than that of the general population (Coppus 2013). Emerson *et al*. (2012, p.6) report that in 2011 in England, the median age at death for people with learning disabilities was approximately 30% (25 years) younger than for people without learning disabilities.

Health and social care service providers have been challenged in recent years by the rapid increase in numbers of older people with learning disabilities requiring their services (Holland 2000; Bigby 2010). Our concern in this paper however is not with specialist learning disability services, but with the exclusion of people with learning disabilities from generic social policy for older adults. As noted above, the dominant policy discourse in relation to increased longevity in the general population is active ageing, but the experiences of older people with learning disabilities have largely been excluded from this discourse. We do not need to look far for an explanation for this exclusion. The historical mass institutionalisation of people with learning disabilities across the Western world was so comprehensive (Thomson 1998) that their existence was effectively expunged from mainstream social policy. It may be helpful here to consider the roots of that exclusion in Britain.

Mathew Thomson (1998, p.13) argues that the 1870 Education Act, which established the principle of mass elementary education, acted as an 'important trigger in the development of the problem of mental deficiency' as it revealed a section of the population whose education could not be provided within an ordinary elementary class. By the early 1890s several local authorities had established special schools or classes and the 1899 Elementary Education (Epileptic and Defective Children) Act urged local authorities to make provision for that special instruction within the state system. However, once these children had completed their 'special' education, the problem of what they should do when they reached school-leaving age became apparent. Because of these concerns, there were plans to set up residential training centres for school leavers where they could be appropriately cared for and protected. In 1898, Mary Dendy founded the Lancashire and Cheshire Society for the Permanent Care of the Feeble-minded. Like many others at the time, she believed that feeble-mindedness was an inherited 'evil' which could only be prevented by permanent institutionalisation. Dendy was also involved

in campaigning for legislation and state institutions for the mentally deficient, as were members of the newly formed Eugenics Society (Jackson 1996; Thomson 1998). Change in the law came with the 1913 Mental Deficiency Act which provided for the identification, certification and permanent institutionalisation of those considered mentally or morally defective. Local authorities established Mental Deficiency Act Committees and employed an Executive Officer 'who was responsible for 'ascertaining' potentially certifiable adults and children' and removing them to the local institution (Potts & Fido 1991, p.20-22).

This wholesale 'removal' of people with learning disabilities resulted in their no longer being viewed as members of mainstream society and there was therefore no need for mainstream policy to attend to their needs. As a result, those families who chose to keep children at home did not receive any help from the state, even when the National Health Service (NHS) was introduced in 1948. When babies with Down's syndrome or other visible learning disabilities were born, parents were advised, 'leave them here and let the NHS look after them'. If they chose not to do this, they had no support at home, not even a school place for the child (Race 2002, p.34). Families did not receive state support until the early 1970s when the Attendance Allowance was introduced and the Education (Handicapped Children) Act 1970 entitled 'severely subnormal' children to an education for the first time. Since then, there has been a major policy shift of deinstitutionalisation of people with learning disabilities across the Western world and most now live in the community. In the UK, resettlement programmes saw people returned to their 'communities of origin' where local authorities resumed responsibility for people who had been admitted to institutions from their area, often many years previously.

Once resettled into the mainstream, people with learning disabilities came under the same legislation as any citizen in need of care and support in the community. This included an assessment under the NHS and Community Care Act 1990 and provision of services under a range of legislation, some of which dated back several decades. The social care needs of people with learning disabilities have continued to be met under generic social care provision, including the recent allocation of personal budgets. The Care Act 2014 enshrines in law local authorities' duties in relation to care and support planning and personal budgets, which were previously set out in policy guidance. The needs of older people *without* learning disabilities are also covered by the same legislation. It is only more recently with increases in longevity of people with learning disabilities, that the needs of older people with learning disabilities have required greater focus in social policy.

There has been widespread discussion of the transnational policy trends of institutionalisation and deinstitutionalisation of people with learning disabilities (eg Mansell & Ericsson 1996). What has been much less evident however is discussion of contemporary mainstream social policy's exclusion of people with learning disabilities. This paper seeks to remedy that omission in relation to the policy discourse surrounding active ageing.

Active ageing and people with learning disabilities

The discussions of active ageing outlined above appear to be focussed on the ageing of an 'ideal-type older person' who is centrally included in the mainstream of

society. To summarise, the policy discourses on active ageing emphasise (i) older people's ongoing contributions to the economy through extending their working lives; (ii) their active civic engagement in the societies of which they are a part; and (iii) a life-course approach to active ageing which focuses on their employment history and the preparations they make for older age *throughout their lifespan*. As we explain below, the experiences of older people with learning disabilities have largely been excluded from active ageing discussions on all three counts.

(i) extending working lives

Emerson *et al*. (2012) cite the National Audit Social Care Intelligence Service figures on the numbers of people with learning disabilities in England in all forms of work (this data is collated by councils with adult social services responsibilities at individual assessments or reviews):

> The figures for 2010/11 show a slight increase (up 0.2 percentage points from 6.4% to 6.6%), in the number of people with learning disabilities recorded as being in some sort of regular work (paid or unpaid) when compared to 2009/10. However, this is still less than the percentage of people with learning disabilities in work in 2008/09 (6.8%). The majority of people with learning disabilities in work were working part-time hours of less than 30 hours a week. The number of people with learning disabilities undertaking unpaid voluntary work has fallen since 2009/10 from 8,275 to 7,715 (a 6.8% reduction) (Emerson *et al*. 2012, p.94).

It is clear from these figures, and other employment research, that few people with learning disabilities have played an active role in the labour market (Beyer *et al*. 2010; Humber 2014). Of those who have participated, work is often part-time, and/or unpaid (Emerson *et al*. 2012). Many people with learning disabilities want to work but the systems and structures required to support their employment are not in place (Humber 2014); it seems particularly inappropriate therefore to suggest that older people with learning disabilities postpone retirement or continue employment in older age.

(ii) active civic engagement

People with learning disabilities are amongst the most socially excluded citizens in our society (Hall 2010). As institutionalised or 'non-economically active' adults, they may have had few opportunities for civic engagement in their younger lives. That's not to say however that they do not desire these opportunities in later life, or that they may not be possible. Indeed there is some evidence to suggest that successful engagement may be easier to achieve in older life. For example, Higgins and Mansell (2009) found that people with learning disabilities who were living in homes for people with learning disabilities experienced better quality of life outcomes in relation to participation in meaningful activity and community engagement than people with learning disabilities living in older people's homes. Stancliffe *et al*. (2014) also report positive outcomes in innovative research exploring 'transition to retirement' for older people with learning disabilities in Australia. Stancliffe *et al.*'s (2014, p.12) study used an 'active mentoring' approach to link existing members of mainstream volunteering or community groups with people with learning disabilities

who were transitioning to retirement and found that 'on the basis of one person with a disability per group', participation in volunteering or community groups was 'a feasible option' for older people with learning disabilities.

(iii) preparations for older age throughout the lifespan

Adopting a life-course approach to active ageing serves to highlight stark differences between the lifespans of people *without* learning disabilities who have largely been economically active, and people *with* learning disabilities who are frequently viewed as passive recipients of lifelong welfare (Kittay 2011). This is particularly so for the generation of people with learning disabilities currently approaching retirement age, most of whom will have lived in learning disability institutions for much of their younger lives. Similarly stark differences are also evident for the vast majority of younger people with learning disabilities who are not in paid employment, nor are they likely to be by the time they reach retirement age (Beyer *et al*. 2010). To suggest that people in this situation take a life-course approach to economic preparation for retirement may be particularly unhelpful. What may be more helpful however is a life-course approach to *learning*. Buys *et al*.'s (2008, p.69) research found that lifelong learning was important to many of the older people with learning disabilities in their research who 'felt that having the opportunity to learn new and exciting skills or activities kept them engaged with their community and in their daily lives'. Indeed, Buys *et al*. (2008, p.70) argue that the older people with learning disabilities in their research 'had similar wants and aspirations to the broader ageing population' but that 'achieving these was often impeded because of a lack of appropriate support or because of the controlling influence of others.'

Conclusion

The history of social policy in relation to people with learning disabilities has been divisive and damaging. People with learning disabilities were removed historically from mainstream society; mainstream social policy therefore had no need to acknowledge their existence. In 2015, people with learning disabilities are part of the mainstream; mainstream social policy should therefore take account of their needs and interests. Active ageing is a contemporary policy tool intended to apply to *all* older people. However, due to its over-focus on employment and economic preparation for retirement throughout the lifespan it excludes the lives and experiences of many older people with learning disabilities. There is a tendency in policy to over-idealise a particular economic model of ageing (Walker & Maltby 2012). Even advocates of active ageing such as Walker (2002, p.134) understand the risk 'that this sort of strategy will become coercive'. Therefore, the imposition of top-down generalities must be avoided through attending to the specificities of varied positive and negative lived realities of older people with learning disabilities (Stenner *et al*. 2011).

To be a more effective policy tool, active ageing must take account of people's diverse lives and experiences. It needs to be a 'dynamic, life course driven concept that taps into people's perceptions and enables them to create their own forms of activity, instead of focusing on a predetermined, limited number of domains, usually developed from an 'expert' perspective' (Boudiny & Mortelmans 2011, p.12). People with learning disabilities themselves are best placed to determine the domains of an

active ageing tool inclusive of their aspirations; such a tool would also be of relevance to the many other older people for whom participation in the labour market has not been the main determinant of their younger lives.

Policy research related to ageing is frequently aimed at solving the 'social problems' of an ageing population. Harding (2004, p5) argues that research of this nature is frequently complicitous with the agendas of public institutions. In order to mitigate against this, she suggests that researchers should, 'avoid taking their research problems, concepts, hypotheses, and background assumptions from the conceptual frameworks of the disciplines or of the social institutions that they serve (the legal, welfare, health, education, economic, military and other institutions)' and should instead 'study up' (Harding 2004, p6); in this case, start research from the lives and experiences of older people with learning disabilities.

The development of *inclusive active ageing* policy (approaches to active ageing which are inclusive of the experiences and perspectives of older people with learning disabilities) require inclusive approaches to research (Nind & Vinha 2014). This entails the involvement of older people with learning disabilities in agenda setting for research, in influencing the course that the research takes, in interpreting findings and in devising and developing approaches to *inclusive active ageing* policy. For without the active involvement of older people with learning disabilities, there is a risk that active ageing policy will continue to reinforce their exclusion.

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