16 The intersectionality of intellectual disability and ageing

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Introduction

Intellectual disability is characterised by significant limitations in both intellectual functioning and in adaptive behaviour, which cover many everyday social and practical skills reducing ability to learn new things (Department of Health, 2001). Intellectual functioning refers to mental capacity, whilst adaptive behaviour spans a range of conceptual, social and practical skills often referred to as daily living skills. Approximately 2% of the population in England have an intellectual disability although fewer than this are known to services (Public Health England, 2015). People with Down's syndrome make up between 15% and 20% of the population of people with intellectual disabilities, with around 1 in every 700 babies born affected by this chromosomal disorder (Centers for Disease Control and Prevention, 2017). There are a range of individuals who are often considered to have an intellectual disability but who do not, including persons with dyspraxia, dyslexia, attention deficit disorder, Asperger's syndrome or some individuals with autism.

Life expectancy globally is increasing for many people with an intellectual disability as a result of improved neonatal care, increased quality of life and improved access to health and social care services (NHS Scotland, 2017). For example, in 1983 a baby born with Down's syndrome often did not live beyond age 25, whereas today the average life expectancy for a person with Down's syndrome is between 50 and 60, with a small number of people living into their 70s (Down's Syndrome Association, 2018). Therefore, people with Down's syndrome of 50 years and over are typically considered as falling into the older age group of people with intellectual disabilities.

Discussion of issues relating to ageing with an intellectual disability throughout the chapter leads to consideration of one of Nancy Fraser's (1996; 2014) key questions – whether social justice requires the recognition of individuals or groups, or if recognising common humanity is sufficient. Whilst Fraser recognises the need for a pragmatic approach, what ought to be recognised depends on what is essential to ensure parity. By reframing support for people ageing with intellectual disability it is possible to argue for an extension of Fraser's social justice framework to give a particular focus on changes associated with

the early onset and progression of dementia in people with Down's syndrome. This calls for a reframing of 'ageing' among people with intellectual disability to reinforce the importance of intersectionality between intellectual disability, ageing and dementia. To do so, this chapter will firstly explore the chronological challenge through the lens of Fraser's social justice framework (1996). Beginning with Fraser's two-dimensional perspective of distribution and recognition, we then reflect on resources and (re)distribution to demonstrate how working in silos is preventing a cohesive approach to supporting people ageing with intellectual disability. Recognition (identity) highlights the lack of preparation, provision and support for people with intellectual disability in later life. We then consider representation with discussion of the extent to which the voices of older people with intellectual disability remain unheard. This takes us on to Fraser's three-dimensional, rather than two-dimensional, approach with recognition of the social injustices faced by this group that are only compounded by age and further age-related disability.

Models of ageing with an intellectual disability

Fraser did not specifically write about intellectual disability, however in the context of disability generally she focused on the social model to support a model of inclusion. As such it is not the 'player', but the unequal 'playing field' that impacts on how far a person is included (Fraser, Honneth and Wolf, 2003). Using Fraser's definition, it seems that if many people with disabilities want to participate and communicate with those in power, they will have to conform to 'ableist' norms. The distinction between impairment and (physical) disability has received much attention over the years with attempts to reorientate the debate by focusing on society rather than the individual. For example, Oliver (1997) highlighted how society further disables 'impaired' individuals through such an ableist structure, thus increasing the potential for dependency.

Older people with intellectual disabilities are a diverse group. Although chronological age is typically used as a trigger to access services and support for older people generally, this is not a useful indicator of the age-related needs of persons with an intellectual disability. Indeed, it presents the first paradox in this chapter. The standard life course model of ageing views getting older as a linear progression through stages and life events with chronological ageing as the norm. Yet, the life course for people with intellectual disability differs significantly in terms of relationships, marital and financial status, number of children, employment and physical health reinforcing the lack of a level playing field but with no option to conform to norms when age, typically 65, is the criteria used in the UK to access age or dementia related services.

When considering theoretical models, this does not make a life course approach unsuitable for people with intellectual disabilities, indeed childhood experiences are crucial as is future planning for older age, however it typically takes a different route (Krahn and Fox, 2013). Grenier, Griffin and McGrath (2016) report a similar tension among the population of people ageing with

a physical disability (see also the chapter in this collection by Westwood and Carey on ageing with physical disabilities and long-term conditions). There has been a shift in generic models of ageing with Foster and Walker (2015), for example advocating for 'active ageing' as a paradigm shift from 'successful ageing', which was derived from development of theories such as continuity, activity and disengagement. The active ageing discourse focuses on encouraging the participation of older adults in society and emphasises the competence and knowledge that older people possess. 'Active' was defined by the World Health Organisation as '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, 12). Whilst this perspective challenges negative stereotypes of older age and emphasises autonomy and participation, it highlights the schism between people with and without an intellectual disability for whom the term active ageing is rarely applied.

Nowhere is this gap more evident than when we consider dementia in people with intellectual disabilities. After age 60, about 6% of adults with intellectual disability will be affected by a type of dementia, with the percentage increasing with age (Janicki and Dalton, 2000; Zigman et al., 2004). However, this rises to 50% to 70% of adults with Down's syndrome in the same age group (National Task Group on Intellectual Disabilities and Dementia Practice, 2012) with a prevalence rate of one in three aged in 50s increasing to nearer two in three from age 60. Indeed, Hithersay et al. (2017) suggest that more than 80% of people with Down's syndrome may experience dementia by age 65 years. Such earlier onset with associated impact on parents who are often primary carers, intellectual disability services and the growing numbers of ageing adults themselves, combine to raise concerns within the health and social care agenda that are not yet reflected or represented in national dementia plans and strategies. People who have intellectual disabilities are mentioned in just 37% of the 79 available plans (Watchman et al., 2017). However, being 'mentioned' cannot be extended to being 'represented' when content is restricted to highlighting the link between Down's syndrome and dementia, rather than suggesting strategies for support in practice or in policy, or when no acknowledgement is given to the differences among this group in terms of age and life experience.

Many people with an intellectual disability experience the same age-related sensory, physical, social and mental health–related conditions as people who do not have an intellectual disability. However, this population will typically die, on average, more than 14 years younger than the population generally, and are significantly more likely to have certain conditions and diseases (e.g. coronary heart disease), some at a younger age (Hatton et al., 2016). Little is known of people with intellectual disabilities' perception of their own ageing; Burke et al. (2014) reported that 57% described their own health to be very good to excellent but had negative views of getting older. This raises the question of how far people with intellectual disability conform to ageing norms and enjoy 'active ageing' (Walker, 2015). This does not only refer to physical activity but to ongoing social engagement in the communities of which older people are

a part. Active ageing should apply to all citizens, including older people with intellectual disabilities, (Foster and Boxall, 2015).

Whilst Fraser wrote that the shift to conform to 'ableist' norms was required to facilitate inclusion (albeit of people with physical disabilities), Knight (2014) argues that such a focus on 'normalisation' is particularly unfair for cognitively and/or linguistically impaired individuals, arguing that attention to communicative diversity is also required. Even though origins of the social model were not intended as an all-encompassing theory of disability but rather a starting point for how society views disability, an over reliance on the social model of disability has been challenged in relation to people with intellectual disabilities (Oliver, 1997). Terminology also throws up a contradiction, with the term 'disabled people' recognised as consistent with the social model, yet in the field of intellectual disability the paradigm has shifted to 'people with intellectual disability'. This is more than just semantics, as it reflects a shift in ideology to a 'people first' and person-centred approach.

In order to understand more about apparent paradoxes in representation of this relatively recent group of people ageing in higher numbers with intellectual disabilities it is first necessary to explore Fraser's concepts of resources and recognition.

Resources/redistribution

Resources relevant to people with intellectual disability are usually controlled by others: accommodation setting, access to health care, social care and support – either provided by family or paid provision. As part of the redistribution of such resources, there is a pattern of viewing intellectual disability and ageing in isolation, and even more so intellectual disability and dementia, rather than seeking to understand what one field can learn from the other. Heller, Gibbons and Fisher (2015) recognised the importance of redistribution and increased partnership between the fields of ageing and intellectual disability whilst Watchman and Janicki (2017) identified the same schism between the fields of dementia and intellectual disability. This also applied at end of life with McCallion et al. (2017) calling for integrative efforts between intellectual disability and palliative care providers alongside specialist training for carers and the involvement of adults with intellectual disability themselves in their advanced care planning.

Consideration of the lack of divergence in models between ageing and intellectual disability will involve exploration of the extent to which older people with intellectual disability fare economically and how this is related to redistribution. Typically, such a focus on injustice is defined as socio-economic; poorly paid and derived from cultural norms with the remedy being recognition rather than redistribution. However, people with intellectual disabilities have a history of exclusion and marginalisation (issues of recognition) and even now their wishes or wants are not always considered in formative decision making (issues of representation). Employment remains beyond the reach of most with

an overreliance on volunteering, for example the national rate of employment for people with intellectual disabilities in the UK barely changed in the 20 years between 1990 and 2010 (Humber, 2013). As recently as 2014, it was mooted by a UK government minister (Watt and Wintour, 2014) that some disabled people could be paid less than the minimum wage to secure employment.

Redistribution cannot be considered without an understanding of where people live and sources of funding for this. Prior to the shift to 'community care' in the UK many people with intellectual disability lived in long-stay hospitals or asylums located physically and socially on the margins of society (Radford and Tipper, 1988). Even as the asylums closed and people moved into nearby communities, this experience of separation and isolation continued, a situation termed the 'asylum without walls' (Dear and Wolch, 1987, 6). Older people with intellectual disabilities are less likely to be married or to have children and those living with parents are often seen in mutually dependent relationships whereby the person with a disability is often the carers for one or more older parents (Cairns et al., 2012). Shared living arrangements are also common with an individual living with one or more peers, also with an intellectual disability, supported by paid carers, with the level of support depending on individual need. The extent of choice and control that has followed this shift to community-based support, whether informal with families or formal with paid carers, remains limited. For example, Kahlin et al. (2015) noted that both choice and control are dimensions of participation that are limited in a shared small group home (two or more people with intellectual disabilities living together supported by social care staff). In reality, participation is limited by the organisation, the environment, staff knowledge and skills.

It is important to extend previously held perceptions of the role of older people with intellectual disability and to remove the notion of being a passive recipient of care and support. We need look no further than family relationships for an example of this. Adults with an intellectual disability may also gain the status of carer, when a parent, older sibling or other person in their life is diagnosed with dementia (Blackman et al., 2014) and they become the primary carer. This will inevitably bring challenges as navigating services can be problematic, but even more so if the services do not recognise the carer's role or efforts simply because they are marginalised because of the perception of their intellectual disability by others. Such instances will become increasingly prevalent as more adults with intellectual disability are placed into primary carer roles in the absence of any other involved family members. This not only requires recognition of their role as carer, but also the need for specialised services and support to enable these roles to be undertaken.

As the person ages and, for some, health needs change significantly, barriers exist to maintaining accommodation or support services. Diagnostic overshadowing (Inglis et al., 2015) can occur when a health professional makes the assumption that a person with intellectual disabilities' behaviour is a part of their disability without exploring other factors such as biological determinants. This can also include physical conditions mistakenly attributed to mental health or

something that is inherent in the person's intellectual disability. As people with intellectual disabilities have a much higher risk of experiencing a variety of diseases and conditions, it is vital that physiological or pathological determinants in behaviour change are explored. For example, gastrointestinal cancers are approximately twice as prevalent in people with intellectual disability and coronary heart disease is the second highest cause of death (Heslop et al., 2013). In the example of people with Down's syndrome and dementia, social care staff may not recognise early signs or the significance of behavioural changes that may indicate the onset of dementia (Watchman 2016). Furthermore, many social care staff will be unfamiliar with dementia, unsure how to adapt services, lack confidence or knowledge to support the individual as dementia progresses or are hindered by financial restrictions on providing the nature of care required for persons with intellectual disability, particularly as dementia progresses (Watchman and Janicki, 2017). Referral and transfer to inappropriate services (often to nursing or residential care facilities where residents are considerably older and staff are unaware of communication strategies) may be initiated, disrupting established routines and social relationships, as well as affecting a loss of a familiar environment and compromise of meaningful relationships with family members and other long-term friendships (Jokinen et al., 2018).

Institutionalisation does not just take place historically in large out-of-area facilities (People First Canada, 2016). It occurs in any place where people are isolated, segregated, and do not have control over their day-to-day lives. Given most countries' historical policies of institutionalising both children and adults with intellectual disability (Johnson and Traustadottir, 2005), the oldest-old are more likely to have a history of institutionalisation – which has led to self-advocates with intellectual disability strongly voicing their opposition to being re-institutionalised due to ageing-related issues. Companionship for many increasingly comes from people who are paid to provide support and proactive support is required to maintain relationships. This can involve a change in the approach to support that may have previously been provided by staff or family. A consequence is that we know little about experiences from the perspective of the person with an intellectual disability and even less following a diagnosis of dementia.

Despite the social model of disability typically being lauded and advocated, we see a shift towards increased medical needs as a dementia progresses – not just dementia-related changes but in addition to the same age-related health problems as other older adults. For some individuals, sensory and mobility impairment, obesity, sleep apnoea and poor oral hygiene can contribute to health challenges. Inequality is seen in health service and inadequate health provision which does not recognise specific needs of older people with intellectual disability. In relation to mental health and well-being, loneliness has been identified as a significant predictor of age-associated physical and mental health difficulties although with very little research to investigate its impact among people with intellectual disability. Gilmore and Cuskelly (2014) proposed that societal views traditionally stigmatise people with intellectual disability and

limit opportunities for social connectivity with others. In turn, this lack of opportunity reinforces negative attitudes.

This focus on Fraser's social justice framework relating to resources and redistribution already indicates the potential for the lack of a cohesive approach when people age with an intellectual disability. The requirement to conform to 'typical' ageing resources and services are beyond both the reach and the capacity of many people with intellectual disabilities with the social model of disability failing to recognise the intersection between lifelong intellectual disability and increased disability associated with ageing, particularly for people with Down's syndrome who are at risk of early onset dementia.

Recognition

Whilst being excluded from distribution of economic resources is recognised as a threat to social justice, for people with intellectual disabilities this is a long-term exclusion with little likelihood of this changing or of having the choices that are available to other sectors of society. However, Fraser also refers to a second type of social justice – the politics of recognition which recognises and celebrates difference, noting that that both distribution and recognition are required for social justice. People who are the most vulnerable whether due to age, complexity of their disability, lack of verbal communication or a progressive condition remain the most marginalised in society. Whilst the *objective* circumstances of some people with intellectual disabilities has improved, many continue to experience discrimination. The extent of discrimination ranges from personal safety, victimisation in the community and disability hate crime, despite the United Nations Convention on the Rights of Persons with a Disability, Article 19 (2006) stating that people with disabilities have a right to a life in the community – not just a house (Beadle-Brown et al., 2014). By ignoring the contribution of individuals who have been positioned as recipients of care, and overlooking their potential to contribute socially or economically, the process of exclusion and marginalisation can only be continued. This is the ultimate 'other' of difference, previously confined to institutional living, albeit in less obvious form, in the policy of 'social inclusion'.

This is never more apparent than when needs change in the case of people with intellectual disability and dementia and raises a further issue of representativeness. Even less is known of personal preferences and experiences of this group as communication and cognition continue to change. Voices remain unheard and what is understood about people with intellectual disabilities is instead framed through the lens of carers perspectives. Whilst general dementia-related literature contains work on the perspectives of adults who are diagnosed with dementia, with reflections on experiences and reflections on what the progression of dementia may mean (Botek, 2016), most of the literature on dementia-related experiences in the intellectual disability field is drawn from the perspectives of family or staff carers (Carling-Jenkins, Bigby and Iacono, 2014; Lin et al., 2014). Limited experiential information is

available from the perspectives of adults with intellectual disability (Blackman, Thompson, Brookstein and Brooksby, 2014; Lloyd, Kalsy and Gatherer, 2007; Watchman, 2014) and almost none is available from research drawn from their personal perspectives (Watchman and Janicki, 2017) emphasising that under-representation in turn informs under-recognition.

Just as the term disability is contested so too is identity, with terminology again rearing its head when we seek to understand sense of identity. Reference to individuals with an intellectual disability and dementia as a 'hard to reach' group, for example in research, perpetuates the stereotype of not being able to communicate with, or hear the views of, people with intellectual disability and dementia. The term 'under-researched' is more appropriate by placing the onus on the researcher and practitioner to facilitate inclusion rather than assuming that, as a group already marginalised by others' perception of their intellectual disability, this is not achievable. A recurring theme in the literature is of not seeking the perspective of the person with intellectual disability with a diagnosis of dementia, not knowing how to do so, and not recognising the potential for naturally occurring activities that may facilitate conversations. Whilst this is not unique to people with intellectual disability (other marginalised groups are also often excluded from studies), it does indicate an on-going issue facing researchers in the intellectual disability field as this does not reflect the changes undergone in intellectual disability services from when historically exclusion was the norm. At the same time, people with intellectual disability do not necessarily identify themselves as 'old' or 'ageing' (Buys et al., 2008). Preference instead is identified for continuation of areas of life that were enjoyed and meaningful, rather than an age-enforced change in circumstances or 'retirement' from services.

All of this means that a contradiction is apparent. Redistribution is less likely to remedy injustice as it is historical as well as societal and cultural. Recognition has more of a cultural focus and is where most shifts have been, however although representation has become increasing positive for many people with intellectual disability, for some this stalls with increased age or co-morbidity. The question must be asked as to how injustice can be remedied in the face of a remodelling of services, reduction in choices and opportunities in day care facilities and an increase in (at times younger) people with intellectual disability placed in aged care facilities and generic care/nursing homes. This often poses dilemmas particularly for individuals with Down's syndrome who are typically considerably younger than other residents and simultaneously staff often feel, whether accurately or not, that they are ill-equipped to support someone with an intellectual disability (Cleary and Doody, 2016). Rather than a person-centred or individualised community-based service, this raises the question of a return to a culture of institutionalised style of living as people get older. However, we have noted that institutionalisation is more than just a building and limitations extend beyond environmental factors. Fraser noted that neither redistribution nor recognition alone could remedy injustice – both are needed together. Looking historically at the experiences of people ageing with

an intellectual disability and the extent to which this group experience bivalent collectively and are excluded from participation throughout the world, suggests that an increase in identity leads to increased participation, with a redistribution of resources being important from both an individual and a service perspective.

Representation

A key issue when considering representation is the extent to which the voices of older people with intellectual disability are represented, whether through self-advocacy or being represented by advocates for people with intellectual disabilities. In many societies and cultures, the person-centred movement continues to emerge and grow, as does the self-advocacy movement, which is seen in both dementia (DAI, 2017; Swaffer, 2016) and intellectual disability populations (The Arc, 2014). Recently, this has extended to consideration of dementia as a disability under the Convention for the Rights of Persons with Disabilities (Shakespeare, Zeilig and Mittler, 2017) although not with unanimous support, largely due to concern over further labelling (Whitman, 2015). Such a changing level of self-advocacy is reflected by increased inclusion of adults with dementia on planning groups, on boards of dementia organisations, and as sought-after representatives at public policy forums (DAI, 2017). This extent of self-advocacy is not yet expressed by the population of people with intellectual disability affected by dementia or their families, nor has it been evident in decision-making levels within national third sector or non-government organisations advocating on behalf of people with intellectual disabilities (Watchman et al., 2017).

The World Health Organization's (WHO 2012) report *Dementia: A Public Health Priority* called for the development and adoption of national dementia plans or strategies to guide public policy and set development goals for services, supports, advocacy and research related to dementia. There are currently 79 worldwide national or sub-national plans and national or non-governmental strategies. Their content addresses such diverse issues such as encouraging research into the causes and eventual prevention of dementia, establishing early diagnosis and treatment programmes, post-diagnostic support, education and training and supports for family carers. Although the WHO report also called upon countries to address the needs of diverse groups within the scope of these national dementia plans or strategies, just 37% of the 79 plans mentioned adults with intellectual disabilities, with most not going beyond noting the connection between Down's syndrome and dementia. Those strategies and plans that included representation from people with dementia in their development did so as members of a task force, working group, or as part of the consultation process. None referred to the inclusion or representation of people with intellectual disability.

Omission of the perspectives of individuals with intellectual disability in both policy and practice limits understanding of experiences of ageing. It leads to an overreliance on proxy reporting; which should be considered a backwards

step in person-centred work. In relation to a diagnosis of dementia, the perspectives of people with intellectual disability must be considered whenever interventions and supports are discussed. Planning is required at an earlier stage for advance directives that guide medical treatment, and for advice or support around relationships, continuity of social networks, and when securing or adapting dementia-friendly housing.

We have looked at lack of representation of older people with intellectual disabilities in a particular context, ageing with dementia. However, we are faced with a more pressing challenge of how far we can hear the voices of people with intellectual disabilities even before they reach older age, given the continued stigma and social exclusion that stems from both medical and societal pressures. Today there is an increasingly public profile of people ageing with intellectual disability with some in the public sphere providing role models for current and future generations of children and adults. Yet, at least 90% of pregnancies are still terminated when Down's syndrome is determined antenatally and each new screening test developed is lauded by the medical community. The public perception of negativity around Down's syndrome is in sharp contrast with individuals' own positive life experiences and hopes for the future. People with intellectual disabilities continue to seek representation in society, yet remain consistently impacted by the decisions made by others without such disabilities.

Conclusion

The extent and complexity of issues affecting people ageing with intellectual disabilities emphasises the importance of understanding factors that influence representation and recognition. This includes addressing the extent of an individuals' participation and choice, which is often determined by others or by an organisation and acknowledges the need for greater support for self-advocacy. It requires that attention be paid to policy or strategy frameworks that do not accurately reflect the reality for people ageing with intellectual disabilities.

Although Fraser did not write specifically about people with intellectual disability, it is clear that the distinction between redistribution of resources and recognition viewed among older people with intellectual disabilities is consistent with her framework. Furthermore, representation is not only an essential requirement, it has been shown how this should be at the centre of social justice. Economic redistribution and cultural recognition can only stem from political representation and nowhere is this more apparent that when we look in the context of getting older with intellectual disabilities and co-morbidities, including dementia. In terms of Fraser's social justice model, this points to presence of inequality and lack of justice and offers potential to extend her previously limited work on intellectual disability.

Rather than older peoples' services, intellectual disability services and dementia services working in silos, Fraser's social justice model can be extended to reframe our approach to supporting people who are ageing with an intellectual disability. Such an approach should place representation at its core, seeking to

understand individual perspectives and developing this to recognise appropriate support as health or cognition changes, and redistributing resources to reflect the reality of ageing with an intellectual disability. This would not only see an improvement in resources available for older people with intellectual disabilities, thus increasing recognition, but it would also promote recognition of the intersection of ageing and intellectual disability, and as appropriate, dementia. In order to do this, the voices and lived experiences of older people with intellectual disabilities need to be better represented to inform and shape the services made available to them. This supports an extension of Fraser's two-dimensional model to three dimensional, noting the ever-present inequality rising from stereotypes and stigma already present for people with intellectual disabilities then compounded by ageing or additional cognitive impairment due to dementia.

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