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Ageing and increased longevity amongst people with intellectual disabilities: an editorial

This special issue of *Quality in Ageing and Older Adults* will be of interest to researchers and professionals interested in the views of older people with intellectual disabilities, and the development of public policy and services to meet the needs of aspirations of this population.

Men and woman with intellectual disabilities are living longer and comprise a growing proportion of this vulnerable population (Emerson and Hatton, 2008). Seen in the light of policies promoting equal rights, this increase in longevity flags up how important it is to understand ageing and longer life in that part of the citizenry which can be defined by life-long deficits in intellectual and social functioning. What kinds of lives are older adults with intellectual disabilities living? Few, if any, will have acquired the properties, pensions and incomes that their peers in the baby boomer generation are enjoying. Nor will their lives have been punctuated by the milestones of career marriage, and parenthood. What, if anything, could reaching retirement-age mean for people who may have spent almost their entire lives in an enclave of welfare services? This can mean encountering services that often fail to meet the needs of older persons with disabilities and in the case of specialist disability services, often struggle to meet their age-related frailties (National Institute for Health and Care Excellence, 2018).

Amongst those people with intellectual disabilities living in their own homes, many will be caring for, or dependent upon, ageing parents. Such arrangements raise important questions about the character and sustainability of intergenerational support. The many disability advocacy groups, that could assumed to be raising such issues and championing the needs of older people with intellectual disabilities, are contrastingly and overwhelmingly focussed on the needs and concerns of younger people. Patients with intellectual disabilities are at a significant disadvantage in healthcare (Michael, 2008), which older people often see as a most important concern. On average, members of this population die some 20-years younger than their peers in the general population, and up to a fifth of these deaths will be from potentially preventable health conditions (Heslop *et al.*, 2014). When intellectual disability, already characterised by social exclusion and dependency, is accompanied by age-related frailties, this confers a “double whammy” of disadvantage. Studies of ageing give paramount importance to physical, sensory and mental decline (Higgs, 2015) setting them in contrast to studies of disability, which it is argued for reasons of political expediency, have tended to neglect the physical body and its frailties (Oliver, 1990). Consequently, conceptualising ageing amongst adults with intellectual disabilities who are doubly disadvantaged requires thinking beyond current orthodoxies. Yet before we can even begin to do this, if we are to think creatively about ageing and intellectual disability, we need to be more thoughtfully engaged with what we mean by intellectual disability.

Progressive policies envision a world in which people with intellectual disabilities can enjoy the same rights and opportunities as their peers without disabilities (see e.g. Department of Health, 2001). Such ideals are exemplified in the UN’s Convention on the Rights of Persons with Disabilities (CRPD) but date back to earlier and still active campaigns for an “ordinary life” (King’s Fund, 1980). These are operationalised by advancing lists of such desirable outcomes as being a part of mainstream society, non-discrimination and more mundane things, like choosing who one lives with. Rarely, however, is this progressive vision squared with the obdurate realities of living with measurable deficits in intellectual and social functioning. The most telling area of collision between

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this progressive vision and the realities of life with a mental impairment concerns equality before the law, and specifically Article 12 of the CPRD.

Based upon the premise that no matter the nature or severity of a person's impairment all people can, and should, enjoy full and equal equality, the CRPD asserts that all men and women with mental disabilities can make and communicate their own decisions if they receive appropriate support. An assertion that glosses over the defining features of living with an intellectual disability, namely, significant cognitive deficits (occurring in the developmental period) with respect to reasoning; problem solving; planning; abstract thinking; judgement; and learning, which adversely impact on a person's ability to function (American Psychiatric Association, 2013). The possibility that a person's intellectual impairment might make autonomous decision making an impossibility is not considered. Also not considered, except to reject it, is the need to assess a person's functional capacity to make one or more autonomous decisions before granting them legal capacity. The reason for this is that such assessments would be discriminatory, as only people with mental disabilities would be subject to such assessments of their mental capacity (United Nations, 2014). This raises the possibility of people with measurable and significant deficits in intellectual and social functioning refusing life-saving medical treatment where is a good chance of survival or disposing of assets without due regard to their value. Some commentators have spoken of the "dignity of risk taking" and the right of persons with mental impairments to fail. A claim which assumes person's with intellectual disabilities are much like their peers in the general population. Yet this, so-called, right to fail, overlooks the fact that persons with intellectual disabilities unlike their peers in the general population have special non-contributory welfare rights, due to their disability, as well as additional legal protections due to their presumed vulnerability, again based upon their disabilities (Turner, 2006). This signals, consequently, something of a conceptual confusion: are persons with intellectual disabilities different from or the same as their peers in the general population? If they are different, how different and in what dimensions? And if the same, on what bases are they entitled to claim protections and welfare rights not available to the general population?

The failure of the progressive agenda to address this issue amounts is to wilfully oversimplify a complex issue that is fundamental to the provision of care and support. Moreover, this over-simplification is a pervasive feature of contemporary policy as it pertains to persons with intellectual disabilities. As I will illustrate below, it can be found in a number of related and overlapping terms, such as "intellectual disability", an "ordinary life" and definitions of disability.

Diagnostically an intellectual disability is defined by significant deficits in intellectual and social functioning as measured using standardised measures of IQ (a score of ≤ 70) and adaptive behaviour, with an onset during the developmental period. Despite the apparent exactness of this definition, it is quite inexact, when it comes to seeing people in the round. In part, this is because the term intellectual disability when used in policy documents often fails to reference the severity of the disability: mild, moderate and profound. When it comes to making choices and social inclusion, the life chances of people with a mild disability when compared to those whose disability is profound are significantly different. There are even doubts as to whether people with profound disabilities are actively intentional with respect to expressing a preference or participating in a social scene (Coupe-O'Kane and Goldbart, 1998). Moreover, as a diagnostic category, intellectual disability (in common with all mental disorders) is based entirely upon signs and symptoms: measures of IQ and social functioning. Unlike other branches of medicine there are no diagnostic descriptions of aetiology (cause) or pathophysiology (the functional changes in the body). As a result, the diagnostic category of intellectual disability, homogenises a population whose disabilities may be the result of a variety of different causes: trauma before or after birth; chromosomal abnormalities; an infection present at birth or occurring afterwards; intrauterine exposure to toxins such as alcohol, amphetamines (as well as other drugs) and environmental pollutants; or malnutrition. This opens a disjuncture between the criteria used to diagnose an intellectual disability and bio-medical research into the causes of that disability. This disjuncture is most apparent where that disability has a genetic origin. For where the genetic origins of a person's intellectual disability are known developments in genetic science (Tartaglia *et al.*, 2007) and neuroscience (Sandman and Kemp, 2007) present opportunities for describing phenotypically patterns of ill health, as well as behaviour (O'Brien, 2002). This holds out the possibility of looking beyond the diagnosed "intellectual disability" to understand the different

bio-medical causes of disability; treating the pathophysiology causes of different conditions and designing services that better meet people's psychological needs (Oliver *et al.*, 2013). The term "intellectual disability" and its identification through IQ scores are little more than an administrative category used in determining whether or not a person is eligible for disability-related welfare services.

The idea of an "ordinary life" challenges the historic exclusion of persons with intellectual disabilities from mainstream society. But quite what an ordinary life might entail for this population, or any other population, is rarely defined, beyond lists of everyday activities and the opportunity to choose. Choosing, where and with whom one lives; the staff who provide support with daily living; how one spends one's time; and at what time one goes to bed (see e.g.: <https://stayupdate.org/a-manifesto-for-an-ordinary-life/>). As suggested above, little consideration is given to how an ordinary life might be an achievable possibility for people with measurable deficits in intellectual and social functioning. Instead, barriers to achieving an ordinary life are formulated, first, in terms of the prejudicial views and practices of mainstream society, which unquestioningly values ability over disability. And second, through a critique of disability services. This critique, by exposing how services prioritise the interests of providers over the needs and aspirations of service users make the case for person-centred services; direct payments; and individual budgets (O'Hara, 2014). Institutional reform, it is argued, will put those needing services in control of the care and support they need. For all its obvious merits, this reform agenda ignores the economic imperatives which define the service economy, as well as the quintessentially relational nature of services (Jordan, 2006). Services are sensitive to cost pressures while efficiency gains are elusive. Unlike goods, which can be standardised and manufactured in bulk, services are not open to such efficiency gains. There are a limited number of service users that a support worker can wash and dress in a morning. This resistance to efficiency gains (Baumol, 1997), from more people being washed and dressed in less time by fewer support workers, means that service providers (be they public, private or third sector organisations) manage costs by substituting skilled and expensive labour for less skilled and cheaper labour. This would mean intensifying the workload by timing to the minute how long particular acts of care should take; pressurising staff to be "flexible" with respect to hours and breaks and introducing remote technologies that reduce the need for face-to-face contact between client and carer. All of these suggest that service users, even ones with their own budgets, will struggle to control and shape the services they purchase. Furthermore, the focus on individual choice overlooks the relational aspect of services. Subjective well-being is as much a feature of what you choose to do as the social context in which you do it, in effect who you do it with. Services designed solely around clients' wishes and aspirations run the risk of requiring paid support staff to support clients in activities they find unengaging, for example, going fishing; unlikely to contribute to a client's well-being, such as eating junk food; require unsocial hours, like nights out on the town; or find morally unacceptable, such as enabling the purchase of sexual services. Unlike goods, services, cannot be produced and consumed without engaging in some for interpersonal relationship, with all the trade-offs that inevitably involves.

Definitions of disability begin and end with the social model. A model that associates disability with discrimination and a call for political action. However, the social model is thought to have little purchase on the phenomena of intellectual disability because it is far from clear how mental impairments can be remedied through changes to the physical environment (Chappell, 1998). Moreover, this model's focus on static disabilities and neglect of the body have prompted some scholars to ask if, despite its political potency, it can offer a satisfactory account of disability (Shakespeare and Watson, 2001). Consequently, there are those who argue for a bio-psycho-social model of disability, believing that life with an impairment cannot be fully understood without acknowledging its bio-medical reality (Shakespeare, 2013). Advocates of a bio-psycho-social model conceptualise disability as a multi-layered phenomenon that encompasses bodily impairment, individual and social psychology, as well as the wider physical and social environment (Shakespeare, 2013). While a bio-psycho-social model seems to offer a comprehensive understanding of disability, it is a model that gives no formal or systematic consideration to the causal significance, or weighting, of its constituent elements. As such it is less of a model and more a checklist of relevant matters (Burns, 2014), and as a list, this tends towards a conceptual anarchy where researchers are free to choose and dispute what weighting to give the constituent elements

(Ghaemi, 2009). Is a person disabled by some aspect of their environment (as in the social model) or by the particularities of their impairment (the biological in the bio-psycho-social model)? Disputes of this nature predictably turn on whether bio-medical diagnoses should be accepted at face value, or treated as social constructions (Pilgrim, 2015). If it is decided that person is disabled by their biology or mental impairment, then they may be unable to make and communicate an autonomous decision. Their right, say, to equality before the law, as set out in Article 12 of the CRPD or campaigns of an ordinary life are at best meaningless or worst, exposes them to potentially harmful risks. On the other hand, if their bio-medical diagnoses are social constructions, on what basis are they then entitled to claim special disability-related rights (Vehmas and Watson, 2014)?

In sum, the progressive policy agenda for person with intellectual disabilities, irrespective of its laudable aims, is an over-simplification of a highly complex issue: the social inclusion and rights of person whose lives are marked by life-long deficits in intellectual and social functioning. Moreover, by neglecting these issues the progressive policy agenda lacks imprecision and is bedevilled by unresolved inconsistencies, and as such, it be doing as much harm to the cause of people with intellectual disabilities, as good. If we are to truly address the needs of an ageing population of people with intellectual disabilities it is imperative that the high ideals of public policy are grounded in the realities of both impairment and age-related frailty. Additionally, services, particularly health services, should make more use of bio-medical understandings of people's mental impairments; that visions of service reform be sensitive to the economic and interpersonal dynamics of service provision. Then, and only then, can we take responsibility for designing policies that will meet the needs of older persons with intellectual disabilities.

The peer-reviewed manuscripts in this special edition of *Quality in Ageing and Older Adults*, representing international scholarship on ageing and increased longevity, highlight the value and specifically important life experiences of older people with intellectual disabilities; environment influences on dementia and intellectual disability; age-friendly communities for older person with intellectual disabilities; and ageing carers. All of these provide timely directions for policy makers seeking to inclusively address the needs of older people with intellectual disabilities and those working with them.

References

- American Psychiatric Association (2013), *Diagnostic and Statistical Manual of Mental Disorders: DSM-5*, 5th ed., American Psychiatric Association, Washington, DC.
- Baumol, W. (1997), "Health care, education and the cost disease", in Towse, R. (Ed.), *Baumol Costs Disease: The Arts and other Victims*, Edward Elgar.
- Burns, T. (2014), *Our Necessary Shadow: The Nature and Meaning of Psychiatry*, Pegasus Books, New York, NY.
- Chappell, A.L. (1998), "Still out in the cold people with learning disabilities and the social model of disability", in Shakespear, T. (Ed.), *The Disability Reader: Social Science Perspectives*, Cassell, London, pp. 211-20.
- Coupe-O'Kane, J. and Goldbart, J. (1998), *Communication before Speech*, Taylor and Francis, Oxford.
- Department of Health (2001), *Valuing People: A New Strategy for Learning Disability for the 21st Century*, Department of Health, London.
- Emerson, E. and Hatton, C. (2008), *Estimating Future need for Adult Social Care Services for People with Learning Disabilities in England*, Centre for Disability Research, Lancaster.
- Ghaemi, S.N. (2009), "The rise and fall of the biopsychosocial model", *The British Journal of Psychiatry*, Vol. 195 No. 1, pp. 3-4.
- Heslop, P., Blair, P.S., Fleming, P., Hoghton, M., Marriott, A. and Russ, L. (2014), "The confidential inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study", *The Lancet*, Vol. 383 No. 9920, pp. 889-95, available at: [http://dx.doi.org/10.1016/S0140-6736\(13\)62026-7](http://dx.doi.org/10.1016/S0140-6736(13)62026-7)
- Higgs, P. (2015), "The social imaginary of the fourth age and the imperative of care", *Gerontology*, Vol. 55, p. 743.
- Jordan, B. (2006), *Social Policy for the Twenty-First Century*, Polity Press, Cambridge.

- King's Fund (1980), *An Ordinary Life*, King's Fund, London.
- Michael, J. (2008), "Healthcare for all", Report of the independent inquiry into access to healthcare for people with learning disabilities, Department of Health, London.
- National Institute for Health and Care Excellence (2018), "Care and support of people growing older with learning disabilities", available at: www.nice.org.uk/guidance/ng96/accessed (accessed 12 November 2019).
- O'Hara, M. (2014), "Want to improve lives for people with learning disabilities? Listen to them", *The Guardian*, Tuesday, 25 November, available at: www.theguardian.com/society/2014/nov/25/learning-disability-support-alliance (accessed 12 November 2019).
- O'Brien, G. (2002), "The clinical relevance of behavioural phenotypes", in O'Brien, G. (Ed.), *Behavioural Phenotypes in Clinical Practice*, Mac Keith Press, London.
- Oliver, C., Adams, D., Allen, D., Bull, L., Heald, M., Moss, J. and Woodcock, K. (2013), "Causal models of clinically significant behaviors in Angelman, Cornelia de Lange, Prader-Willi and Smith-Magenis syndromes", *International Review of Research in Developmental Disabilities*, Vol. 44, pp. 167-211.
- Oliver, M. (1990), *The Politics of Disablement*, Macmillan Education, London.
- Pilgrim, D. (2015), "The biopsychosocial model in health research: its strengths and limitations for critical realists", *Journal of Critical Realism*, Vol. 14 No. 2, pp. 164-80.
- Sandman, C.A. and Kemp, A.S. (2007), "Neuroscience of developmental disabilities", in S.L.O. et al. (Eds), *Handbook of Developmental Disabilities*, Guilford Press, London.
- Shakespeare, T. (2013), *Disability Rights and Wrongs Revisited*, Routledge, London.
- Shakespeare, T. and Watson, N. (2001), "The social model of disability: an outdated ideology?", in Barnartt, S. and Altman, B. (Eds), *Exploring Theories and Expanding Methodologies: Where we are and where we need to go*, (Research in Social Science and Disability), Vol. 2, Emerald Group Publishing Limited, Bingley, pp. 9-28.
- Tartaglia, N.R., Hansen, R.L. and Hagerman, R.J. (2007), "Advances in genetics", in Odom, S.L., Horner, R.H., Snell, M.E. and Blacher, J. (Eds), *Handbook of Developmental Disabilities*, The Guildford Press, London.
- Turner, B. (2006), *Vulnerability and Human Rights*, The Pennsylvania State University Press, University Park, PA.
- United Nations (2014), "General comment No. 1 Article 12: equal recognition before the law", United Nations.
- Vehmas, S. and Watson, N. (2014), "Moral wrongs, disadvantages, and disability: a critique of critical disability studies", *Disability & Society*, Vol. 29 No. 4, pp. 638-650.