

## Editorial

### Disability and Aging: International Perspectives

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“Empirically, we need to remember these facts: barring sudden death, those who are aging and those who have a disability can be only artificially separated at a particular moment in time. Or except for the possibility of sudden death, everyone with a disability will age, and everyone who is aging will acquire one or more disabilities” (Zola, 1989, p. 6).

“Rather than merely read old age as disability, or disability as akin to old age, it is crucial to consider how an older person’s body read as having a disability is different from a younger person’s body read as having a disability. Similarly, it is crucial to consider how an older person’s body read as having a disability is different from an older person’s body read as not having a disability” (Chivers, 2011, p. 22).

Population aging is taking place in nearly all countries across the world. A 2015 report by the United Nations suggests that globally, the number of people aged 60 and over is expected to double between now and 2050. Presently, this phenomenon is most pronounced in developed regions, but is increasingly an issue for developing countries (Kudo, Mutisya, & Nagao, 2015). On the one hand, global population aging is celebrated as an overcoming story, which confirms culture’s triumph over nature. This perspective is illustrated in the U.S. State Department and National Institute on Aging’s 2007 publication, *Why Population Aging Matters: A Global Perspective*, which opens with the assertion, “Global aging is a success story. People today are living longer and generally healthier lives. This represents the triumph of public health, medical advancement, and economic development over disease and injury, which have constrained human life expectancy for thousands of years” (2007, p. 4). At the same time, aging populations are also routinely represented in terms of a social problem, a demographic crisis, and an omen of an apocalyptic future (Gee, 2002). The dominant narrative suggests that left unchecked, population aging undermines the sustainability of health systems and economies; appropriately managed and monitored, it represents an unparalleled opportunity for countries’ development.

Whether this Janus-faced approach to understanding population aging points to triumph or ruin depends in large part on how the relationship between disability and aging is defined. At times, the relation between disability and aging appears clear and unambiguous; as in research and policy reports that show a direct relation between population aging and increases in the prevalence of disability within countries (Chen et al., 2016; Statistics Canada, 2013). This approach is animated by the assumption that if populations continue to age at the current rate, the absolute number of persons with disabilities can also be expected to increase; in part, because

age brings changes in health and functionality. However, there is also a growing body of literature within research and policy that recognizes that prevalence varies by age, as well as by gender, sex, race, ethnicity, culture, geographic region, and by the nature of impairment (Warner & Brown, 2011; WHO, 2015). This work emphasizes the diversity of aging, and calls for policy initiatives that are responsive to the complexities of aging with and into disability, in place of policies that include disability and aging under one umbrella (Priestly & Rabiee, 2002; Putnam, 2007; Zarb & Oliver, 1993). Rather than focus exclusively on incapacity and functionality, this approach calls for consideration of disabling social structures and barriers.

Within current aging-related research and policy, the relationship between disability and aging is often oversimplified and underdeveloped (Chivers, 2013; Cook & Halsall, 2012; Putnam, 2007). Reductive understandings of disability and aging have consequences for how older disabled adults are understood and treated (Stone, 2003). Despite empirical evidence that suggests otherwise (Woods et al., 2016), disability is regularly assumed to be a product of unsuccessful aging (Martin et al., 2015), and aging as an obstacle to living well with a disability (Gilleard & Higgs, 2013).

This special issue of the *Review of Disability Studies: An International Journal* (RDS) includes eight original articles that analyze how disability and aging appear within research and policy in Canada, the United States, Australia and Switzerland. The issue features empirical research, policy analyses, reflexive methodologies, critical theory and art; all of which expose and challenge disability and age related myths and misconceptions. Articles illustrate the key themes, issues and debates shaping current knowledge and policy related to disability and aging. Authors consider the relationship between disability and aging in its fulsome complexity via analyses of chronological age and life course perspectives; social participation and inclusion; representations of aging well with a disability in media and policy; discursive constructions aging-as-disabling in lived experience; social and cultural norms regarding disability and aging, and by considering the strengths and limitations of current methodologies and theoretical approaches and the transformative power of art. This issue highlights the valuable contributions that interdisciplinary approaches which include disability studies perspectives can make to current understandings of population aging, and shows how global population aging matters from different perspectives.

### **Rethinking Theory, Policy and Practice**

Toni Calasanti and Kathleen Slevin (2001) remark that, “Old age is a social location into which people grow” (Calasanti & Slevin, 2006, p. 12). Amanda Grenier, Meredith Griffin and Colleen McGrath offer a unique perspective on this assertion in, “Aging and Disability: The Paradoxical Positions of the Chronological Life Course.” In this paper, Grenier, Griffin and McGrath explore locations of age and disability as they are conceptualized in institutionalized

models of the life course. They suggest that disability represents a challenge to normative conceptions of age based on chronological stages. However, they also observe that impairment, disability and age become conflated in late life. Their paper charts the effects of the separation and conflation of aging and disability across the life course on cultural narratives, policy and practice, paying particular attention to structured dependency, and proposes new directions for life course policy.

### **Improving Research**

How can research practices better understand the intersection of disability and aging in order to enhance individuals' well being? What methodological challenges exist in this regard, and how can more effective methods be designed? Stuart Wark, Miranda Cannon-Vanry, Marie Knox, Marie Parmenter, Rafat Hussain, Matthew Janicki, Chez Leggatt-Cook, Meaghan Edwards, and Trevor Parmenter address this important question in "Securing Personal Input from Individuals Aging with Intellectual Disability: Do Differing Methodologies Produce Equivalent Information." As the authors point out, the increased life expectancy of individuals with intellectual disabilities has dramatically increased over the past few decades. From public policies to family-based and institutional caregiving, a better understanding of individuals' needs and expectations can help improve their quality of life and wellbeing. Capturing such information is particularly challenging when existing methodologies adopt singular and restrictive conceptions of communication based on normative ideals. How can these challenges be addressed, such that individuals facing communication barriers can be meaningfully engaged in decisions about their lives? In exploring these issues, the authors delve into the qualitative-quantitative divide by examining the utility and effectiveness of two contrasting assessment tools. Their findings will be of great interest to policy makers and practitioners in helping design assessment methods that can support communication, meet individuals' needs and bridge understanding between actors.

### **Understanding the Nuances of Social Participation and Inclusion**

There is a wide body of research that demonstrates the importance of social participation, inclusion and connectedness to individual health and wellbeing. For older adults or disabled people, regular patterns of social participation can be limited by a change in location, the death of friends and family, inaccessible built and social environments that produce limited mobility and/or limited ability to communicate. Given its importance, what can be done to ensure that individuals have the opportunity to socially engage—whether this be in a formal or informal atmosphere? Are there any particular barriers or challenges to those who are both senior and disabled that prevent them from meaningful social participation and inclusion?

Emilie Raymond and Nadine Lacroix tackle this issue in "To Include or Not to Include Them? Realities, Challenges and Resistances to the Participation of People with Disabilities in

Seniors' Organizations." Their participatory action research project engaged with a senior's organisation that was exploring this very question—to include or not to include. They unveil a microcosm of practices that point to the importance of understanding both individual and environmental contexts. This sets the framework for the implementation of practical guidelines for organisations to create more inclusive environments.

### **Reframing the Relationship between Disability and Aging**

The field of disability studies has long combated pervasive discourses on ableism that manifest in everyday language and popular imagery and are reproduced in social, political and economic structures. In a similar vein, gerontology has long fought against ageism—the notion that old age is synonymous with frailty, dependence and decline. Both fields have had a great deal of success in combating these stereotypes and they have often done so together, since the two are linked. But has some element of the successful aging movement, which has gained such traction internationally, detracted from the disability agenda? Does framing aging as “successful” when individuals are youthful and nondisabled, thus cast those who are old and disabled as “unsuccessful”? Does this framing reproduce systems of oppression?

Social gerontologists Chris Gilleard and Paul Higgs remind us, there has also been a “relative absence of ageing” in disability studies (2013, p. 82). Critical scholarship has explored the socio-political, cultural, economic, and subjective dimensions of ‘becoming disabled’. Yet, there has been limited attention to the transformations that shape how disabled people age. Gilleard and Higgs assert that this failure is a product of “incommensurable paradigms of disability” in disability studies and social gerontology (2013, p. 80). While disability studies perceives disability identity as a source of agency, social gerontology assumes that disability is a natural condition of “becoming old”. As a consequence (Gilleard & Higgs, 2013, p.82):

“While representing oneself as disabled provides a potential site of agency and entitlement for those who are not old, adding an identity of agedness, unlike for example those associated with gender, race or sexuality, restricts more than it enhances the space within which the embodiment of disability can be presented, practiced, and re-presented.”

Hailee M. Gibbons explores these issues in “Compulsory Youthfulness: Intersections of Ableism and Ageism in “Successful Aging”. Her paper forwards the neologism of “compulsory youthfulness” to examine the cultural prominence of successful aging and its consequences for the disability and aging agenda. By examining how systems of oppression intersect across these domains, she lays bare some inherent contradictions—thus illuminating the need to reframe such discourses such that combating ageism does not detract from the disability agenda.

In “Coverage of Aging Well of Individuals Aging with a Disability in Canadian Newspapers: A Content Analysis,” Gregor Wolbring and Boushra Abdullah share the results of their framing analysis of textual representations of individuals aging well with a disability within news media and social policy. In doing so, their paper offers key insights concerning the role that media and policy play in reproducing what Gilleard and Higgs refer to as incommensurable paradigms of disability. Wolbring and Abdullah analyze and discuss the significant underrepresentation of individuals aging well with a disability. They note that when disability and aging do appear, they are framed from medical perspectives, and emphasize lack of ability, rather than social disablement. Impairment is understood as something negative, and positive aspects of aging with a disability are rarely if ever discussed. News and policy reports treated disabled people and older adults as two distinct groups, and failed to reflect the needs and realities of individuals aging with a disability. They conclude with a call for more representations that focus on the abilities of individuals aging with a disability to experience their social environments in a positive way.

### **(De)Constructing Aging-as-Disabling**

In “‘My Body Feels Old’: Seniors’ Discursive Constructions of Aging-as-Disabling,” Yvonne R. Teems examines how a disability studies perspective can be used to support critical understanding of the aging body, and what she refers to as, “the dialectical space between the material and discursive body.” Through a grounded theoretical analysis of interviews she conducted with older adults, Teems shows how older adults construct the aging body as disabled in myriad ways. Her interpretation of findings is shaped by a phenomenological approach that she has developed using literature from both the fields of disability studies and cultural gerontology. As such, this work serves as a bridge between the two fields and offers a valuable interdisciplinary contribution to phenomenological understanding of the relationship between disability and aging.

Francesca Rickli considers the significant role that assessment can play whether and how older adults with mobility disabilities can age successfully in their homes and communities in, “No Longer Disabled’ – Reflections on a Transitional Process Between Disability and Aging in Switzerland.” Rickli’s examination includes a qualitative analysis of interviews with disabled seniors. She illustrates how the Swiss social security system fails to support their transition from retirement, transitioning them instead into a “less entitled category of citizenship.” “No Longer Disabled” concludes by questioning the normative paradigm of successful aging, and emphasizing the significant role that social networks play in supporting people in aging at home.

Public health perspectives frame the relationship between disability and aging within discourses of population aging (WHO, 2015). References to disability focus on chronicity, comorbidity, and culturally recognizably age-specific illnesses and impairments, such as

Alzheimer's disease and other dementias. However, even as Alzheimer's disease and other dementias are routinely represented as specific to older adults, they are just as routinely represented as a "severe" form of disability and as such, external to "normal aging". In "The Becoming-Subject of Dementia," Katie Aubrecht and Janice Keefe critically analyze current attention to person-centred and relational approaches to dementia care within global policy reports as an occasion to dwell with the swell of the "grey tsunami" of population aging. Aubrecht and Keefe's analysis traces parallels in the narrative structure of stories of dementia caregiving in national and international policy reports, personal accounts and popular culture. Their findings show how dementia is constructed as an abnormal, albeit expected, condition of population aging, and suggest that a relational approach is not necessarily free from disablism. The meaning and practice of person-centred dementia care is structured by Western cultural conceptions of personhood, and are actualized within geopolitical contexts that are organized by interests that extend beyond those of the person with dementia or their immediate care relations.

### Redefining Disability and Aging

Elaine Stewart's artwork in "A Thousand Threads" and accompanying description captures the overarching theme of a renewed recognition of the need for critical engagement with the meaning and materiality of the relationship between disability and aging. This theme weaves together the various papers in this collection, and is eloquently articulated by Stewart in terms of a relation to labels. She says, "Myself, I cannot just push a label aside again. I want to own it. I want to define it. And then, as an artist I want to illustrate it." All of the articles have engaged with questions of representation as a key aspect of making sense of the relationship between disability and aging. However, within current research and policy such questions are rarely, if ever posed. An animating aim of this issue has been to disrupt unexamined relations to disability and aging, and to highlight the promise and potential of interdisciplinarity and international perspectives in approaching the relationship between disability and aging differently.

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