

THE AGING–DISABILITY NEXUS

Edited by Katie Aubrecht,
Christine Kelly, and Carla Rice



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Disability Culture and Politics

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This series highlights the works of emerging and established authors who are challenging us to think anew about the politics and cultures of disability. Reconceiving disability politics means dismantling the strict divides among culture, art, and politics. It also means appreciating how disability art and culture inform and transform disability politics in Canada and, conversely, how politics shape what counts as art in the name of disability. Drawing from diverse scholarship in feminist and gender studies, political science, social work, sociology, and law, among others, works in this series bring to the fore the implicitly and explicitly political dimensions of disability.

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Introduction

KATIE AUBRECHT, CHRISTINE KELLY, and CARLA RICE

Textile artist Anna Torma's series *Red Fragments* depicts intricate and detailed red-threaded embroidery that over the course of the series evolves to looser, more abstract, and at times knotted, tangled, and frayed pieces. The series documents the multi-textured and multi-temporal materiality of bodies, knowledges, and art practices in relation. To us, it also signifies the weaving together of the strands that craft a life – the warp and weft, folds and frays, wrinkles and curves, and unsewn spaces that re/make us even as we re/make it. Torma's work, featured on the cover of this book, encapsulates the complex, creative, and generative spaces of aging and disability.

Many academic articles, government reports, media accounts, novels, and personal memoirs take up questions of aging and disability, and gesture toward both dystopic and utopic scenarios for the future of aging and disabled lives. Most often, these sources draw on demographic information to imagine what a future with more older and disabled people means, feels like, and looks like, while pressing for particular socio-economic responses to “deal” with this likelihood. As we know, populations are indeed aging in nearly every country. Although the trend is most visible in Europe, North America, and Japan, there is growing attention to population aging and accompanying demographic transitions in the Global South (United Nations 2019). A 2015 report by the United Nations suggests that globally, the number of people aged sixty and over is expected to double between 2015 and 2050. The World Health Organization (WHO 2011) and United Nations

(2013) assert that increasing proportions of older persons have spurred parallel changes in disability demographics worldwide. Societal changes and global health inequities have also informed who is most likely to develop a disability and what types of disability we can expect – that is, there are disproportionate numbers of aging women who are living with chronic illnesses (Sadana et al. 2016; WHO 2015).

On the one hand, global population aging is celebrated as a sign of advancement in health care, success, and economic prosperity. It is treated as proof of Western scientific triumph over both nature and the limits of the body (Aubrecht and Krawchenko 2016). Disability studies scholars highlight how narratives in which individuals overcome the limits of their minds and bodies perpetuate pervasive disability tropes and tired old cultural scripts (Dolmage 2014; Rice et al. 2015). The shadow to these heartwarming narratives is that they also individualize experiences of disability, rather than politicizing embodiment (or recognizing its socially mediated nature). Dominant tropes of disability as a tragedy to be defeated, a pathology to be cured or killed, or a sign of social ill buttress the neoliberal fantasy of individual will and mastery that shapes contemporary austerity agendas. They reinforce the underlying imperative that suffering must be overcome, which in turn rationalizes the fates of those individuals who fail to exercise control over their bodies, minds, and senses, and thus are condemned to experiencing poverty, social exclusion, and institutionalization (Clare 2014; Mintz 2007; Rice et al. 2018).

Although population aging is also commonly seen as a triumph over the body, it is often presented as a harbinger of an apocalyptic future (Gee 2000). Older people are frequently depicted as a catastrophic drain on families and economies, and as an impeding tsunami that will overwhelm social and health infrastructures (Barusch 2013; Charise 2012; Katz 1992; Lundgren and Ljuslinder 2011). These competing descriptions stress an urgent need for more complex, theoretically informed considerations of what it means to age amid a highly monitored global cohort and in the context of a myriad of research, social, and political/policy responses (Baars et al. 2006; Powell 2014).

Critical disability studies has long utilized the concept of temporary able-bodiedness (Garland-Thomson 2001; Kafer 2013) – that disability is dynamic and fluid, and that it can occur at any point in life, especially as one ages. The concept also asks us to recognize that aging *with* a disability differs from aging *into* disability and that experiences of aging and disability are further complicated by a multitude of other identities, positionalities,

socio-economic forces, global and local histories, cultural and community configurations, and geopolitics (Aubrecht and Krawchenko 2016; Chivers 2011; Lamb 2015). At the same time, disability activism has been critiqued for excluding older adults (Jönson and Larsson 2009). This collection is driven by the assumption that creative and generative possibilities emerge when aging is situated in a disability politics and when interpretations of disability take account of the weaving of material, social, and cultural relations in and through which the meanings of bodies as young or old are made and unmade. The interfaces between embodiments, environments, social and political economies, and cultural messaging are precisely the places in which disability and aging are created and experienced. It is also at these interfaces where taken-for-granted meanings and materialities of disability and aging may become exposed, frayed, and unravelled.

National, international, and transnational scholarship that explores the aging–disability nexus is surprisingly limited, but what does exist is innovative and thought provoking (Basting 2005; Burke 2008; Chivers 2011; Katz and Marshall 2004; Kontos and Martin 2013; Mintz 2007; Raymond and Grenier 2013; Silvers 2000; Wendell 2000). More commonly, however, scholars rely on medical paradigms, researching co-morbidities, complex needs, dependency burdens, and other reductive visions of disability. We are in the midst of an exciting cultural turn in age studies (Katz 2014) and critical gerontology (Baars et al. 2013; Twigg and Martin 2015), with a focus on embodiment and intersectional analyses, especially at the junctures of disability, gender, and sexuality. In the field of disability studies, there has been important yet limited engagement with the particularities of aging with and into disability (Priestley 2003). Recent work has drawn on gerontology to understand and explore dementia (Aubrecht and Keefe 2016, 2017; Bartlett 2015; Basting 2005; Boyle 2014, 2017; Bülow and Holm 2016; Grenier, Griffin, and McGrath 2016; Shakespeare, Zeilig, and Mittler 2017; Thomas and Milligan 2017). The newly emerging dementia studies (Innes 2009) offers a testament to the power of dementia as a site for thinking through the aging–disability nexus from the perspectives of aging studies and disability studies, but it provides only one of many possible entry points and intersections.

In short, most scholars and researchers, whether situated in disability studies or in aging studies, have yet to consider in a comprehensive or substantive way the development of truly interdisciplinary and intersectional scholarship that focuses on the nexus of disability and aging. Critical work on aging crosses disciplines that are not usually in conversation, which

means that it can be difficult to locate. There is also a tendency in popular culture and mainstream media to conflate disability and aging (Chivers 2011) and to subsume one under the other without giving adequate attention to the tensions that shape how disability and aging are known, experienced, and responded to. This book intervenes among these narratives of the intersection of aging and disability, drawing on critical social and cultural perspectives. We hope to serve as a counterpoint to the more common representations of aging/disability in the form of epidemiological statistics, social and health policy problems, and individualized stories of overcoming.

The chapters in this volume – national, international, and transnational in scope and approach – address an important absence in cultural gerontology and disability studies. They provide a richly theoretical yet accessible anthology that can inform public engagement, cultural creation, education, policy, and practice while also serving as a primer for students, scholars, artists, and activists working at the intersection of aging and disability. The chapters represent theoretical, empirical, and pedagogical discussions from established and emerging scholars, as well as new and experienced activist-academics. We use a broad definition of disability that incorporates physical, mental, sensory, learning, and intellectual differences, as well as the various forms of deafness and chronic illness. Our definition of aging is similarly wide in recognizing the inevitable interplay of forces – biological, social, cultural, and historical – that co-construct the meanings, contours, and experiences of aging bodies and lives. This collection takes up three main thematics: conceptualizing intersectionality at the aging–disability nexus; analyzing the overlapping and distinctive politics of care surrounding aging and disability; and theorizing the timescapes and landscapes of disabled and aging lives.

Conceptualizing the Nexus

Part 1, “Conceptualizing the Nexus,” explores the theoretical intersection of disability studies and cultural gerontology/aging studies. Conceptualizing the aging–disability nexus challenges us to think in *intersectional* ways about the politics and cultures of aging and disability studies. Intersectionality emerged from feminist and critical race studies – in particular, scholarship and activism by black women who pointed out how their multiple identifications created unique experiences of oppression that were not captured by either feminist or anti-racist movements and thinking (Crenshaw 1991; Rice, Harrison, and Friedman 2019). Although disability studies and

aging studies are otherwise progressive fields, they often fail recognize that people with disabilities age and that aging gives rise to disability; and they have failed to fully analyze how disability and aging intersect with other experiences, locations, and social forces. Like other fields and activisms invested in counter-hegemonic theory and culture building, disability studies and aging studies run the risk of erring on the side of sameness at the expense of difference when, for example, the concept of successful aging hinges on neoliberal values that celebrate only those older adults who are unimpaired, independent, and self-sustaining. Or when disability theories and activisms privilege the experiences, needs, and interests of those whose cognitive capacities function in normative ways, marginalizing those with age-related dementia and other cognition-associated disabilities. These examples indicate the need to advance disability and aging studies and activisms, and to locate and push their intersectional foci, through dialogue.

The critiques of aging studies and disability studies for their lack of intersectional perspectives are not new; the intersectionality theories at the heart of such critiques are still evolving. Rooted in black feminist thought and the activism of the Combahee River Collective, intersectionality was fully developed into a theory by legal scholar Kimberlé Crenshaw (1989, 1991), who employed the metaphor of the traffic intersection to make visible the multiple interweaving causes of discrimination against black women and others who experienced overlapping oppressions. Intersectionality theorists argue that unique experiences of marginalization lie at the intersections of social identities in specific times and places; they can be overlooked and even exacerbated when one uses a singular identity framework (Carastathis 2016) or fails to consider the colonial histories and legacies that shape contemporary realities and social relations. Further, intersectionality suggests that one person can experience both privilege *and* oppression, depending on the situation at hand. From an intersectional perspective, identities are multiple, fluid, embodied, and urgently important in understanding the social world.

Since its foundation, feminist and critical scholars from various disciplines and theoretical perspectives have elaborated on how to use the concept of intersectionality in their own inquiries. Some have deployed it to theorize anti-essentialist approaches to subjectivity and group affiliation, whereas others have used it to explain micro-level experiences of multiply marginalized people or to study macro-level interactions between experiences and social structures. Still others, such as Jasbir Puar (2012), use the

Deleuzian concept of assemblage to reimagine the intersections as events rather than a static nexus of discrete identities and social structures: momentary, contingent, dynamic. Building on Puar's work, Carla Rice (2018, 537) argues that intersectionality may need to be reconfigured when considered through the lens of embodiment. She contrasts the *intersectional* framework with an *intrasexual* one. In the former, "inter" means between or among groups, and this approach might interrogate how identities as "separate categories are produced and reproduced in stable social structures." By contrast, the latter, where "intra" means inside or within, might approach "identifications in more emergent, entangled, and embodied terms as coming to be through shifting symbolic, structural and organic forces co-implicated in their corporealization."

Indeed, intersectionality is broadly taken up in a wide array of disciplines and is becoming popular – some would suggest too popular – in empirical research (Bauer 2014; Green, Evans, and Subramanian 2017). Carla Rice, Elisabeth Harrison, and May Friedman (2019) trace a genealogy of intersectionality and hone in on three critical movements in its theoretical elaboration and adoption in research. In considering these twists and turns, the authors show that many empirical researchers have embraced the theory mainly to manage complexity and diversity in their research, ignoring or glossing over its historical roots in black feminist thought. Rice, Harrison, and Friedman (2019, 418) also state that intersectionality "orients to social justice, so research utilizing intersectional analysis must commit to justice in its processes and knowledge production." This is a key element in keeping the transformative potential of intersectional research and theorizing both alive and moving. Notably, scholars in disability studies and aging studies have yet to espouse these approaches or to theorize the specific intersections, or intrasections, of these markers as they materialize across temporalities and spaces.

Aware that intersectionality theory has been mobilized in many ways, *The Aging–Disability Nexus* poses critical questions of disability and aging at the intersections. For example, what happens when we operationalize intersectionality in aging and disability scholarship and politics, and position this nexus at the centre of inquiry? This volume explores the multiple, variable, and embodied experiences of aging and disability, emphasizing their overlapping oppressions, agencies, and activisms. Moving beyond an analysis of the nexus as singular or static, it pushes into the complex "alchemy of layered, yet unstable, markers and forces of difference and privilege" (Rinaldi, Rice, and Friedman 2020, 4) that shape the aging dis-

abled experience. Chapters serve as vignettes or cases, each of which dwells with aging and disability as discursively produced, as socially embedded in time, and as body-mediated moments in place.

Politics of Care

Part 2, “Politics of Care,” draws on the many empirical overlaps among older and disabled people, especially in various continuing care settings. The five chapters in this part of the book highlight policy and practice considerations while referencing the theoretical engagements discussed in Part 1 and elsewhere. Building on and responding to feminist, philosophical, and other critical scholarship on care, disability studies has contributed vibrant and evolving critiques of care, exposing the presumptions of the caring and rehabilitative professions and the violence of caring encounters and responses to disability that result in coerced dependencies and institutionalized segregation (Ben-Moshe, Chapman, and Carey 2014; Kelly 2016, 2017; Kröger 2009). Disability scholars illuminate how the organization of care reflects societal views about disability and the role of disabled people in society. These complex critiques and contributions have altered care scholarship and directly influenced policies (Yoshida et al. 2004). Indeed, one cannot simply assume that care encounters are inherently good or well intentioned; rather, they must be rethought as tense, politically charged microcosms within which government policies and broader politics are enacted.

When a formal care provider interacts with an older and/or disabled person, that encounter is mediated by how disability and aging are viewed in policy frameworks (Armstrong and Braedley 2013). For example, when policy perceives disabled individuals as passive patients, the provision of care may be tied to certain locations (home or institutions but not community), administered in a top-down manner, and provided in task-based, incremental ways. More fulsome views of age and disability, however, can generate more promising practices. For instance, if older people are understood as fundamentally valued members of society who may be experiencing isolation and loneliness, the allocation of care hours/dollars would consider the social role of the care worker in an asymmetrical yet reciprocal caring relationship. This premise also affects the workers themselves, because “the conditions of work are the conditions of care” (Armstrong and Daly 2017, 14). How care workers are treated directly influences how older and disabled people experience care.

Conceptualizations of care, aging, and disability that are enmeshed in policy frameworks directly affect the work and experiences of providing and

receiving assistance with daily activities. Yet, it is not always, nor even often, possible to identify the conceptualizations that support the best care outcomes or working conditions. We must accept the difficult truth that even policy frameworks informed by nuanced understandings and positive intentions will not wholly resolve the harms and tensions of care. As Maria Puig de la Bellacasa (2017, 11) notes, we must be cautious around care that seems “untouched by trouble.” That is, she asks us to participate in “the ongoing, complex, and elusive task of *reclaiming* care not from its impurities but rather from tendencies to smooth out its asperities – whether by idealizing or denigrating [sic] it.” The challenge for policy thus lies in continuing to improve experiences and working conditions while accepting that the perpetual and irresolvable troubles of care will evolve at the same time. The contributors to our collection do just this – trouble care – resisting efforts to smooth it out.

Timescapes and Landscapes

Part 3, “Timescapes and Landscapes,” focuses on spatially oriented as well as time- and futurity-oriented theoretical discussions in disability studies to consider what these discussions mean within the context of aging. Disability scholar and activist Eli Clare (2014) situates disability not in the individual body, but in physical and imaginary spaces, within and through which the meanings of bodies are made and undone. Just as disability is created and experienced at the interface of embodiments and environments, the same can be said of the aging body. The chapters’ critical analyses of ageism (Calasanti, Slevin, and King 2006) and disablism (Goodley, Lawthom, and Runswick-Cole 2014) illustrate the multiply located and experienced effects of psychological, socio-economic, political, and historical oppression. Using cases from the global North and global South, authors question the meaning and materiality of difference and development, exploring the temporal, spatial, and broader geopolitical tensions that shape how age and disability are known and experienced. Disability studies and development scholar Shaun Grech (2011, 95) reminds us that “questioning development also involves contending with the contemporary and hegemonic neoliberal globalising projects it promotes.” Thinking across diverse social and cultural expectations about development and participation, chapters chart the material contexts and conditions that determine when and where aging and disability intersect, and why locating these intersections matters.

At this moment in critical disability theory, time emerges as another construct that is ripe for theorization of the aging–disability nexus. Normative

understandings of time determine how futures have been imagined by delimiting who is seen as able to participate in envisioning and revisioning futurity. These imaginings often mobilize fantasies of technological and biomedical advancement to render disabled (and aged) bodies extinct. However, if we rethink disability as human difference, as biodiversity and variation, as emerging in experiences of aging, and as materializing through the ways we work, live, and organize our worlds – as an integral part of the story of humanity – the notion that biomedicine and technology will “fix” it once and for all begins to seem fantastical, utopic, and naive. In her now classic *Feminist, Queer, Crip*, Alison Kafer (2013) interrogates how biomedicalized cultural logics have rendered disability as a site of “no future.” To challenge such exclusionary fantasies, Kafer (2013, 27) calls us “to enter into theoretical discussions about ... futurity, but also for us to wrestle with the ways in which ‘the future’ has been deployed in the service of compulsory able-bodiedness and able-mindedness.” Where disability figures in the future, she argues, it often serves as a metaphor for dystopia, signifying a grim burden and never-ending tragedy. When thought of in relation to futurity, disability is imagined as the antithesis of progression, thus rendering a future with disability unimaginable (Rice et al. 2017). Kafer (2013, 3) posits an alternative future for disability, a “crip” futurity, which she describes as a yearning for an “elsewhere – and perhaps, an ‘elsewhen’ – in which disability is understood otherwise: as political, as valuable, as integral.”

In activist research with people who have dementia, aging studies scholar Ruth Bartlett (2014) likewise challenges exclusionary visions of normative time. As experience, embodiment, and cultural identity, dementia disrupts normative understandings of memory and, with it, of time. Although such critical analyses of dementia would support imagining disability and disability futures anew, the experiences of people with dementia are underrepresented in disability studies (Bartlett 2014; Bartlett and O’Connor 2010). Bartlett’s work intervenes in dominant logics that assume people with dementia are neither capable of contributing to reshaping futures nor members of a broader disability community that creates culture and claims citizenship and justice.

Chapter Summaries

In Chapter 1, Amanda Grenier, Meridith Griffin, and Colleen McGrath focus on how age and disability are imagined in assumptions about the life course. They consider false distinctions and conflation of aging and disability, and how these influence responses to older and disabled people.

They argue that the intersection of aging and disability is shaped and devalued by notions of dependency, which determine the allocation of services.

In Chapter 2, Lucy Burke examines two novels about living and dying with dementia to analyze current discourses about the condition. She discusses the implications of the relatively recent separation of aging and dementia, not least the emergence of the latter as the condition that is most feared by adults in late middle age. Her chapter explores whether the political insights of disability studies would be useful in re-engaging dementia studies with ideas of aging well.

Chapter 3, by Sally Chivers, explores the effects of austerity policy agendas on older and disabled people. She interprets guidebooks and online “tips and tricks” sites that target caregivers who are deciding whether to look after a relative at home or seek other arrangements. Her chapter allows us to better interpret care advice and to set up mechanisms that diminish the need for self-advocacy. It suggests that applying a critical approach to care advice may help to reclaim the intersection of aging and disability.

In Chapter 4, Monique Lanoix discusses the physical response of individuals with Parkinson’s to music and dance. Using the writings of dance theorist Maxine Sheets-Johnstone (2014), Lanoix examines the manner in which dancers with Parkinson’s destabilize the close link between control and agency. She argues that meaning making has a deep corporeal component, which does not necessitate a notion of control as mastery; indeed, meaning can be created with less stringent requirements.

In Chapter 5, Maggie FitzGerald disrupts the separation of aging and disability in policy realms. She demonstrates how aging with a disability and aging into disability generate unique experiences that are not fully reflected in long-term-care policies. She suggests that a critical ethics of care can illuminate the varied intersections at play here. This ethics of care understands human experience as relational and contextual yet does not valorize care as a moral ideal without risk and violence.

In Chapter 6, Christine Kelly traces the legacies of disability activism in efforts to expand self-managed home care for Ontarians. Disability activists and policy-makers often promote such care as an alternative that puts control in the hands of users by providing cash to arrange their own services. Kelly offers tentative thoughts on a tense point of divergence in the perspectives of aging studies and disability studies: the role of residential care in the options for continuing care.

Rachel Barken and Alan Santinele Martino consider age relations as expressions of power and inequality in Chapter 7. They present the findings

of a qualitative study on older people who use home care, exploring how study participants enact both age and disability. Aiming to build bridges between critical age and disability scholarship, the authors argue that older people both reproduce and challenge assumptions associated with aging and impairment.

In Chapter 8, Margaret Oldfield and Nancy Hansen draw on personal ethnography to contrast two women's experience of care: Susan had an intellectual disability and Helen had dementia. The authors show the ways in which age and disability interface to create opportunities and barriers to express agency in connection with care relations and sociality more broadly. The chapter highlights instances in which power was exercised over Susan and Helen, making links to their identities and care arrangements.

In Chapter 9, Poland Lai incorporates disability critiques of care into a close reading of a long-term-care regulatory framework in Ontario. Demonstrating that disability studies emphasizes choice, independence, and consumer control in care arrangements, she considers how these factors are reflected in the Long-Term Care Homes Act of 2007. Drawing on a relational approach to law, she argues that blanket endorsements of choice and control have little meaning in long-term-care residences.

Part 3 opens with Nadine Changfoot and Carla Rice's invitation to perceive aging with and into disability as distinct and integral multifaceted experiences. The authors discuss six films made through Re•Vision: The Centre for Art and Social Justice by people with mind/body differences. They argue that new materialist theory can expand possibilities for aging and disabled people by not limiting their futures. Bringing this critical lens to bear in analyzing the films, they provide alternatives for understanding relationships between non-normative embodiments and temporalities.

In the following chapter, Anne McGuire investigates an optimistic re-branding of the aging body, one that is grounded in the cultural understandings of neoliberal and capitalist times. Asking on what terms the aging body is welcomed into the neoliberal good life, she fleshes out two prominent and contrasting figures – the boomer and the zoomer. She suggests that the boomer is haunted by ableist assumptions regarding what Rod Michalko (2002) terms the “useless difference” of disability, whereas the zoomer is all about utility, mobility, and progress.

In Chapter 12, Katie Aubrecht and Akwasi Bofo examine how framing the aging–disability nexus in terms of difference and development may be understood in relation to colonization. Concentrating on South Africa, they analyze how the assumptions of international dementia strategies construct

African countries and people as undifferentiated and lacking development. They note the “Eurocentric secularism” (Grech 2011, 91) at play in Western reports that emphasize the “backwardness” of African interpretations of and responses to dementia. Thinking at the intersection of postcolonial studies, disability studies, and cultural gerontology, they read international dementia strategies and reports as Orientalist texts (Said 1979).

In Chapter 13, May Chazan explores aging and HIV-related disability from the perspective of older female caregivers in KwaZulu-Natal, South Africa. She thus addresses the limited attention paid to this topic in South Africa, where HIV/AIDS has had the most profound impact. Chazan disrupts many assumptions about aging, even those of aging studies. The HIV/AIDS epidemic, extreme poverty, and geopolitics have fuelled stigmatization of youthful bodies (due to their association with disease), as well as the sense that reaching the age of forty is an achievement.

Part 3 closes with Chapter 14, in which Nathan Kerrigan suggests that the experiences of disabled older people who live in the British countryside have been overlooked. He proposes that social exclusion is the reality for them. The perceptions of the local community and of the older people who self-identify as having a particular disability illustrate the nature, extent, and impact of social exclusion in the countryside. The chapter notes that the problem is worsened when older people with disabilities are racialized.

The volume ends with a dialogue between two well-known figures: aging studies scholar Ruth Bartlett and disability scholar Alison Kafer. Interweaving various themes from the preceding chapters, they speak in nuanced ways, asserting the urgent need to adopt a citizenship lens and for crippling time to imagine and materialize livable lives for aging and disabled people. They make visible the negotiations involved in analyzing the aging–disability nexus from multiple perspectives and in building coalitions across these constituencies. Collectively, the chapters in this book illustrate the exciting range of theories, methodologies, and resources that can be used to explore the nexus.

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PART 1

CONCEPTUALIZING
THE NEXUS

1

Aging and Disability

The Paradoxical Positions of the Chronological Life Course

AMANDA GRENIER, MERIDITH GRIFFIN, and COLLEEN McGRATH

The experiences of older people and those with disabilities are commonly understood to unfold through patterns, events, and transitions throughout the life course.¹ Lives are also seen as progressing against a backdrop of age-based markers, social relations, institutional boundaries, and cultural expectations. Heavily influenced by structural functionalist thinking, the standard model of the life course views individuals as moving through normative stages in a relatively linear manner, with certain events occurring at predictable times, such as childhood, adulthood, and later life (see Hockey and James 2003).

Chronological age is at the heart of what is predominantly characterized as “normal” human development: it configures lives through a set of structures, institutions, and expectations of the institutionalized life course (see Kohli 2007; Mayer 2004). Though scholars have explored the shifting interpretations of the life course and growing old, they have paid less attention to the intersection of aging and disability or to how it affects groups that do not fit into institutionalized structures or dominant cultural frames (for exceptions, see Minkler and Fadem 2002; Priestley 2003; Raymond and Grenier 2013). However, it is precisely the complex relationship and differential positioning of disability and aging that create unique tensions.

This chapter focuses on the locations of age and disability as presented in institutionalized models of the life course. It explores the paradox that arises when experiences at the intersection of aging and disability are set against

the normative and chronological view of aging and the life course. It then outlines how the experiences and expectations of aging and disability have been structured and institutionalized. This includes how policies and practices such as those organized around dependency have shaped what is known or assumed about aging and late life. We then turn to how debates about age, disability, and success destabilize taken-for-granted assumptions in the context of population aging.

Age and Disability across the Life Course

If we consider perceptions of the life course as a means to understand the relationship between individual experience, social structures, and cultural expectations, we see that aging and disability are paradoxically positioned. Chronological age dominates understandings of the linear model of life (Grenier 2012; Hockey and James 2003). Aging is both a biological and a socio-cultural process that is primarily measured in years for individuals and in lifespans or life expectancies for populations. Yet, social relations and cultural interpretations also play a role in configuring aging and late life. Whether one refers to longevity, the age of eligibility for certain public services, or the cultural constructs of third and fourth age that are defined around leisure lifestyles and decline (Gilleard and Higgs 2000), aging is generally associated with a particular period of life. It is accompanied by normative expectations that are institutionalized through structures and the frame of the life course itself. The greatest of these is the master narrative of decline, which manifests in the joining of age and impairment,² and in the ethos of activity, productivity, and success that reinforces the imperative of staving off disability and decline (see Gullette 2004; Katz 2005; Minkler and Fadem 2002).

The position of disability, however, challenges the dominant view. Unlike aging, impairment and disability can occur at any moment in a person's life and thus cannot be fixed in time. Given this, disability is often positioned conceptually and/or practically (by means of a service or response) outside the standard view of the life course. For example, people with disabilities commonly move through school, family, work, retirement via separate systems or programs that cater specifically to them (Hockey and James 2003). Understandings of disability are also organized according to the binary of normal versus abnormal. Distinctions are made between impairment as a functional or physical limitation of the body (Burchardt 2004) and disability as a feature of social, environmental, or attitudinal barriers that limit full participation in the community (Stone 2013). These distinctions draw

attention to the separation of disability from the life course, point to the roots of social identities and identity-based claims, and scratch the surface of the paradox between aging and disability.

Whereas aging and disability are separated throughout the early phases of life, they become conflated in late life. This occurs through attention to the biological realities of aging, such as co-morbidity and impairment, and via the socio-cultural narratives of decline and dependency. Successful aging and leisure lifestyles have gained prominence since the mid-2000s, but both models upon which theories of aging are built (e.g., continuity, activity, disengagement) and the cultural narratives that shape responses to older people are grounded in the idea that we naturally decline as we grow older. This is similarly the case in institutional practices, where assessment and eligibility for aid concentrate on impairment and loss of function. Yet, the differential positioning of age and disability across the life trajectory and the conflation of age, disability, and impairment in late life hold important insights for understanding the tensions that exist. Everyone ages, and many people eventually experience health problems, but impairment and disability are not automatically a part of growing old (Oldman 2002). This idea – that aging can be free of impairment – exposes a crucial problem in existing views of aging, disability, and the life course.

The separation and conflation of age and disability create tensions and reinforce the exclusion of people with disabilities and older people in differing ways. First, whereas disability is isolated as abnormal, age and impairment become conflated as normal and expected. Second, responses to aging (and disability) are configured in a medicalized view of disability as impairment that prioritizes function (Smart 2006). In fact, nearly all references to disability among older people use the word “impairment” rather than “disability” (except in the case of people aging with disabilities, who are distinguished as a population group).

A third result occurs in the realm of social identities and cultural narratives. Older people can be reluctant to cross the boundaries of identity and to align with the “other,” a label that is frequently assigned to persons with disabilities as a result of able-bodied norms (Morris 2001). They may also resist being classified as disabled (Oldman 2002) and may align themselves with successful and disability-free trajectories to counter the negative implications of age/impairment (i.e., the fourth age). Similarly, people who are aging with disabilities may position themselves outside the chronological category of “old” to resist the narrative of decline. Often unrecognized in theory and practice is how these identity-based responses may be both a

function and a representation of a chronologically configured life course. Where the ideas about older people and those aging with a disability meet, however, is in the practical allocation of dependency-related services and the devaluation of lives at the intersection of age and impairment. The dominance of normative time-based discourses related to age-based chronology and impairment thus creates and sustains the paradox of aging and disability. It represents a significant challenge for theory, policy, and practice in the context of population aging.

Policy, Practice, and the Configurations of Dependence

A focus on the structural nature of predominant societal responses to the intersection of age and impairment reveals how the separation and then conflation of aging and disability influence policies, practice, and configurations of dependence. Policy frameworks and service structures that concentrate on chronological age and normative patterns shape formal (as well as informal) responses to people with disabilities and those who are aging. In many ways, policy discourses on disability resemble those on aging, with both emphasizing the work-welfare divide of exemption from adult labour. Herein, the social categories of “disabled” and “old” are at least partially constructed by their relationship to work and the economy through what is referred to as “structured dependency” (see Oliver and Barnes 2011; Phillipson 2013). According to the idea of structured dependence, aging and disability are an economic problem – with both locations relegated to situations of dependency because they are outside the means of production. Structured responses thus create forms of exclusion that take place through relationships with paid labour and biomedical interpretations of impairment.

That said, the structured responses to aging and disability can vary a great deal. Here, medicalized interpretations of impairment and disabled bodies inform approaches to dependency, recognition of diagnosis or condition, and eligibility for social programs in ways that sustain the separation and conflation of disability and aging. Standard life course models position age as indisputable, based on date of birth, though this ground for eligibility is shifting. Yet, the status of impairment and/or disability is contested and can fluctuate between medical definitions and the identity claims of an individual or group. Such differences can result in non-recognition and/or ineligibility for services, wherein some people are classified as not disabled or not disabled enough to qualify for services or compensation schemes (Lightman et al. 2009). Policy and services thus structure dependency and reinforce medically defined impairment or disabled identity in service claims,

thereby reinforcing cultural interpretations or expectations. Whereas age is a gateway to the post-retirement pension, impairment (determined by medical classification and/or standard assessments of function) provides access to supports for older people, and disability furnishes access for those who have disabilities but are not old.

Major differences exist between how persons who are aging with a disability and those who have acquired one in later life fit into institutionalized frameworks and constructs. The former are often seen as disabled (and may perceive themselves in this way), whereas the latter are commonly labelled as impaired or elderly (Jonson and Larsson 2009). Hakan Jonson and Annika Larsson (2009) argue that the chronologization of human life encompasses three stages: education, work, and post-retirement. So, where some people with disabilities participate in the educational system or the labour force and thus follow the institutionalized life course, some take the path of specialized education or receive social benefits, such as income support, that flag their dependence and identify them as “other.” Such conceptualizations create boundaries between insiders and outsiders and emphasize the importance of rights- and identity-based claims. This is especially the case where access to programs or services is predicated on being categorized as disabled or frail. What this means in terms of the paradox is that the separation from the standard life course is reinforced through a structured dependency rooted in classifications of the disabled body. This plays out differently in earlier and later life, primarily organized around medical definitions that provide access to services and compensation schemes. We turn now to the second part of the analysis to demonstrate the complexities of the ways in which dependence re-enters language and practices, and whereby disability and impairment become conflated in late life.

Considering structured responses draws our attention to a shift that occurs as people with disabilities age, resulting in a conflation of disability and aging. At the practical level, the change occurs as individuals are transferred from disability-based income support programs to those based on age, such as the government pension. If this is accompanied by changes in income or medical coverage, they also signify a fusion of disability and age where the standard chronological life course is concerned. People who have a lifelong disability, or one that occurs before they retire (usually at sixty-five), move into a period of tension between age-based rights and decline. This transition (and in particular the age at which it occurs) can have substantial implications in everyday lives. Age, and the associated process of defining people as old rather than as disabled, begins to alter eligibility for services

and compensation relative to younger counterparts (Jonson and Larsson 2009). In some ways, this transition can expand access (i.e., universal entitlements to social assistance based on age), but benefits may also be reduced due to assumptions that normalize impairment and decline as one grows older. This turning point in the configuration of structured dependency and its associated socio-cultural implications offers insight into the paradox of disability and aging. In particular, it reveals how differential responses to older people and people with disabilities, when organized around age, can structure inequality and conflate disability and aging in ways that are problematic for both groups, especially where services, meanings, and life-long identities are concerned.

The impacts of variations in structured dependency are most obvious in connection with retirement. Initially conceived as a right and a type of social protection, retirement was a reward for a lifetime of contribution. In this case, a form of legitimacy accompanies dependence in late life, given a presumed lifetime of workforce participation. However, in terms of both economic benefits and status, the protection is deeply rooted in participation in the standard life course, as employment-related financial contributions determine pension benefits. This raises two challenges for older people and those with disabilities. First, though universally awarded and thus constituting recognition, the protection has the greatest benefit for individuals who have been employed throughout their adult lives. In current systems, access to this protection is differential: for example, people with disabilities often have lower levels of workforce participation and will thus receive a smaller pension than those who have been consistently employed. The associated sense of deservedness that is linked with a connection to the labour market will thus be diminished for people with disabilities as well. Late life poverty and inequality, and the associated stigma or exclusion, are therefore not only systemic but also unequally distributed and can become increasingly pronounced as time passes.

The second related issue is that shifting institutionalized frameworks, such as measures to raise the age of eligibility for the government pension, will pose the greatest challenge for older people whose ties to work have been tenuous, unstable, or non-existent. This applies to many people with disabilities who may have experienced discrimination in terms of accessing employment, individuals who cannot work due to health issues, and those who leave the labour force earlier than retirement as a result of illness or injury or to care for themselves or others. Given this, the offer of retirement

as a legitimized dependent identity is only partially available when disability enters the equation.

This differential structuring provides insight into the paradox of aging and disability, where the life course is shaped by social and cultural constructs that include social policy and organizational practices (see Phillipson 2013). Initiatives that are designed to confront dependency through social participation (especially with regards to work) will continue to have differential impacts as effects are carried into late life. The discourse of participation resonates with long-standing advocacy for access, inclusion, and normalcy (Priestley 2003), but the impacts of this discourse will depend on whether this access is rhetorical or meaningful, as well as on whether it can alter the systemic exclusion that presently exists (Raymond and Grenier 2013). Frameworks of participation, if enacted in line with the experiences of people with disabilities, could challenge the separation from the life course and the subsequent accumulation of inequalities. Yet, to what extent are these measures actually concealed efforts to get everyone to work, thus reducing government spending and forms of social protection? And further, how will the merger of dependent groups that occurs through employment and the extension of the working life play out, where the backdrop for aging is one of “success” that is disability-free?

The Focus on Success and the Future of Life Course Policy

Since the turn of the twenty-first century, the negative view of aging as dependency has shifted to a positive image organized around success. Positive discourses, which emphasize active, successful, or healthy aging, were intended to challenge the perception of aging as a period of decline and dependency (Katz 2001–02). However, this approach has proven counterproductive, where health disparities serve to position certain groups outside the boundaries of success (Asquith 2009; Raymond and Grenier 2013). The focus on success often means that disability in later life is framed as a personal failure (Laliberte Rudman 2006) or an example of failed aging (Boudiny 2013). The problem is that as positive aging discourses, including the well-known successful aging paradigm proposed by John Rowe and Robert Kahn (1997), prioritized good health, independence, continued engagement, and social connectedness (Asquith 2009), they also drew on the boundary between health and illness in late life, which relegated disabled bodies to unsuccessful aging and/or the fourth age (Grenier 2012). This rift between healthy and ill/impaired bodies, which has been solidified through the narrative of success,

became one of the major, if not the dominant, frameworks for aging and late life. The unintended result, where aging and disability is concerned, was in producing a return to the normal-abnormal binary that is embedded in the view of the standard chronological life course.

Although disability across the life course has not been subject to the frame of success, the ideal of success leaves no space to meaningfully articulate experiences of aging that are accompanied by impairment. In this case, older people with impairments become located outside the standard and the ideal because freedom from the negative valuations of age is possible only by avoiding illness and impairment. In *Feminist, Queer, Crip*, Alison Kafer (2013) presents this problem as reflective of a curative imaginary, in which the idea of a future can be conceived only through purging or solving disability. Too much disability and/or need for assistance, as with a walker or a wheelchair, quickly tips a person into aging by means of impairment, which is obviously the antithesis of success.

A number of contradictions thus emerge at the intersection of aging and disability. On the one hand, lifelong disability can destabilize the coupling of age and impairment by rendering the question “when does one become old?” difficult to answer and by challenging the link between age and impairment. However, the conflation of impairment, disability, and aging, operationalized through standard models of aging and reinforced through frames of success, creates an impossible target for older people with disabilities, who, in turn, may be marginalized, receive fewer opportunities for meaningful social engagement, and ultimately be excluded from mainstream society (Laliberte Rudman 2006). It is also problematic because it privileges lower levels of disabilities and facilitates the powerful illusion that a disability-free life can be achieved as one ages.

Similar issues are present in the ideologies, policy constructions, and practices that justify the systematic oppression of those who live with disability (Barnes 2005). A number of disability policies remain rooted in a narrow medical model (Horejes and Lauderdale 2014), as well as in social and cultural expectations of normalcy that privilege and project able-bodied values (Terzi 2004). Drawing on the work of Judith Butler, Robert McRuer (2006) describes this focus as compulsory able-bodiedness. Aligned with the controversy associated with successful aging, people with disabilities are often evaluated and categorized in relation to their degree of dependence, with these assessments forming the basis for recognition of their disability and, often, service response (Fine and Glendinning 2005). The social model of disability attempted to shift this attention from the functional limitations of

individuals with impairments to the problems caused by disabling environments, barriers, and cultures (Priestley 2003). Social model rhetoric, if not policy, is now enshrined in the publications of a host of government and voluntary agencies that deal with disability and related issues (Barnes and Mercer 2010; Shakespeare 2006). Yet, as Colin Barnes (2012) points out, these policies had only a marginal impact on the growing numbers of people who were labelled as disabled, in rich and poor countries alike. Further, they left the tensions and contradictions with regard to disability and impairment in late life unarticulated and unaddressed.

Recent work in disability studies has turned to the importance of reconfiguring and imagining spaces to include the widest array of bodies and minds (Kafer 2013; McRuer 2006). Concepts such as *crip futurity* (McRuer 2006) and *feminist, queer, crip* (Kafer 2013), for example, question current constructs and practices, and envision shared/sustainable futures. Tackling ideas about disability, Kafer (2013, 3) outlines how its depiction as tragedy and the absence of a future, or as “what ends one’s future,” is a major part of the problem (also see Meekosha and Shuttleworth 2009). It is precisely this interpretation – combined with the devaluations of age – that portrays impairment in age as a negative state.

Feminist, queer, crip, and/or crip futurity provide a theoretical frame to uncouple lives from the standard view of the life course. The focus on fluidity of categories within this theoretical frame, for example, has drawn attention to the importance of the contextual nature of identity formations and transformations, as well as changing micro-macro social relations and cultural meanings (Meekosha and Shuttleworth 2009). This includes recognition of the limitations of the social model, particularly that insistence on the removal of barriers may be unrealistic (Shakespeare 2006; Shakespeare and Watson 2001) and that approaches to date may have excluded important dimensions of people’s experience (Barnes 2012). Kafer’s (2013) crip theory holds potential for rethinking age and disability, suggesting an ideal vision for the future (and futures) and theorizing the possibility of alternative temporalities.

Clearly, the categories and relationships embedded in policies and practices need to be reconsidered, and an inclusive and sustainable vision for the future must be developed. The paradox of disability and aging and the implications of tragedy and failure highlight the need to fully investigate the connection between policy and experience. Particularly relevant are approaches that detail how trajectories of disadvantage can produce inequalities throughout life – ill-health and impairment may occur due to many

forms of disadvantage, such as homelessness and the colonial practices that are directed at Indigenous people. Important in their own right as social issues, such illustrations draw attention to the problem we are addressing – the idea that late life impairment is interpreted as aging, irrespective of the ways in which lives have been damaged by factors such as poverty, sub-standard housing, contaminated water, inadequate sanitation, and colonialism. It is this challenge of recognizing the structural nature of impairment combined with valuing disabled lives that will preoccupy our immediate future.

Population aging represents a unique context characterized by greater numbers of older people, increased longevity (including among groups who have historically lived for a shorter time), and more years of chronic conditions or impairments (as features of longevity and medical and technological advancements). What this means is that impairment and disability are likely to become more prominent aspects of our so-called greying societies and will probably prompt a reconsideration of needs, public spaces, and care, if only due to the sheer volume of people. Given this, it is entirely possible that the current idea of success may shift or be exposed for what it is – an illusion. Population aging and the future thus underscore the need to grapple with the tensions between disability and aging, and to create spaces where older people with disabilities (lifelong or acquired) can see themselves in frameworks and live without the stigma of being defined as unsuccessful.

One suggestion for achieving this is to draw on life course approaches to policy (McDaniel and Bernard 2011; Priestley 2003). According to Susan McDaniel and Paul Bernard (2011), principles of the life course perspective can open new possibilities for policy interventions across institutions, such as education, labour and employment, family policy, health care, and social assistance. Although life course policy is currently underdeveloped, the suggestion is that trajectories, patterns, and relationships – when configured as more than individual trajectories and not limited by age or stage-based understandings – may hold potential to better target responses across the life course and into late life. In this vein, life course policy may offer a flexible frame that underscores trajectories of disadvantage and works across complex social and policy environments to “bring disadvantaged groups into being an advantaged group” (McDaniel and Bernard 2011, S10).

However, this route is not without its challenges. Approaches to policy may be so embedded in standard institutionalized notions of the life course that age-based assumptions are simply replicated. Further, life course policy

may achieve little in changing socio-cultural perceptions of late life as impairment and decline and of disability as tragedy. If this policy is to play a useful role, it must be detached from chronological approaches and the paradoxical relationship between disability and aging. Here, we suggest two considerations: first, balancing views of inequality with reconfigured relations of access and inclusion, and second, that social and cultural configurations, such as those enacted in policy responses, recognize and support the lives of older people and people with disabilities, rather than positioning them as examples of tragedy or failure. Indeed, we suggest that future versions of life course policy should be grounded in Kafer's (2013) utopian vision of a shared and sustainable future that provides a basis for reimagining individual identities and social justice.

Conclusion

The constructs, frameworks, and responses to disability and impairment across the life course and into late life require review. There is a need to reconceptualize living with a disability in late life not as tragedy or devoid of a future but as reflective of a wide range of experiences and realities (see Kafer 2013). Our argument is that a good proportion of the problem lies in the reliance on standard institutional life course models that are rooted in chronological age and ideas of structured dependency, and that interpret experience of impairment as negative. This is characterized by the tendency to separate or position disability outside the life course in earlier periods, only to reintroduce impairment as a central feature of aging – an intersection of the decline and tragedy narratives. Viewing experience as fluid and permeable across time may be the first step in recognizing the complexity of the relationship between disability and age, and may loosen the bind of current approaches. Here, we suggest that linking scholarship on fluidity in disability studies and gerontology may be particularly fruitful and that the notion of futurity may help to resolve the existing paradox.

Further, the separation of disability and aging from the life course, and the conflation of aging and impairment, creates a paradox that is overwhelmingly dominated by social and cultural notions of individual success and failure. Critical approaches have focused on either disability *or* aging, thereby overlooking the relationship between the two, across the life course and into late life. Fixed frameworks grounded in the standardized life course may well have reached their limit, but how to define responses that incorporate aging, impairment, and disability is not yet clear. Though a refined version of the life course may hold potential, current interpretations may

fall short of the rethinking that is required, especially where particular social locations butt up against practices of recognition or eligibility for public services (Grenier 2007). We suggest that aging, impairment, and disability be reconsidered via critical perspectives that acknowledge the interplay of power within and between structures, systems, contexts (including the socio-cultural), relationships, and experiences. This may include linking critical studies of aging with notions such as those in Kafer's (2013) perspective of feminist, queer, and crip.

Rethinking and reconfiguring responses to aging/impairment and disability/aging will require an approach capable of considering personal, social, political, and cultural expectations of disability and aging as a means to inform policy and practice. A significant challenge lies in addressing the exclusionary practices and normative assumptions that continue to shape responses to and experiences of disability, impairment, aging, and late life, and to configure spaces of meaningful involvement. We urge that researchers, policy-makers, and practitioners work closely with older people and people with disabilities to discover solutions to the existing paradox. Only through ventures that link voices, accompanied by insights from disability studies and the critical perspectives of aging and late life, can we create understandings and future visions where the needs of older people with lifelong disabilities and acquired impairments can be meaningfully included in the social and cultural spaces of a re-envisioned life course.

Notes

- 1 Throughout the chapter, we use person-first language of older people and persons with disabilities, a deliberate linguistic practice to place individuals (and their experiences) before the diagnosis and/or condition. We also apply the word "disability" to disabilities across the life course, and we use "persons aging with disabilities" when speaking of a population group. We recognize the challenges posed by the language (especially when moving across fields such as critical gerontology and disability studies) and know that leading advocacy work employs "disabled persons" to shift responsibility from the individual to society (Morris 2001). An interesting treatment of the language in disability studies can be found in the introduction to Alison Kafer's *Feminist, Queer, Crip* (2013, 4). She discusses the tension between biomedical and corporeal realities and the social configurations of space, noting that both exist in tandem and must be acknowledged.
- 2 "Impairment" refers to the practices of assessment and framing of disability in late life. In late life, the dominant use of "impairment" is related to the biomedical assessment that typically comes to the fore with regard to older bodies and care. In using this word, we draw attention to the differences that exist in the language used in

earlier and later periods of late life, and we problematize how this language structures and shapes experiences. This distinction is part of the paradox.

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