

Review of Disability Studies: An International Journal  
Volume 12, Issue 2&3  
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## Table of Contents

### Editorial

[Old and Disabled - Disabled and Old](#).....p. 3  
Megan Conway, PhD, Editor

### Forum

[Disability and Aging: International Perspectives](#).....p. 3  
Katie Aubrecht, PhD, Forums Editor, Tamara Krawchenko, PhD, Co-Guest Editor

### Research Articles

[Aging and Disability: The Paradoxical Positions of the Chronological Life Course](#).....p. 11  
Amanda Grenier, Meredith Griffin, Colleen McGrath  
Canada

[Securing Personal Input From Individuals Aging with Intellectual Disability: Do Differing Methodologies Produce Equivalent Information?](#).....p.28  
Stuart Wark, Miranda Cannon-Vanry, Marie Knox, Marie Pamentier, Rafat Hussain, Matthew Janicki, Chez Leggatt-Cook, Meaghan Edwards, Trevor Parmenter.  
Australia

[To Include or Not to Include Them? Realities, Challenges and Resistance to the Participation of People with Disabilities in Seniors' Organizations](#).....p. 49  
Emile Raymond and Nadine Lacroix  
Canada

[Compulsory Youthfulness: Intersections of Ableism and Ageism in "Successful Aging" Discourses](#).....p. 70  
Hailee M. Gibbons  
USA

[Coverage of Aging Well of Individuals Aging with a Disability in Canadian Newspapers: A Content Analysis](#).....p. 89  
Gregor Wolbring and Bushra Abdullah  
Canada

[“My Body Feels Old”: Seniors’ Discursive Constructions of Aging-as-Disabling](#).....p.107

Yvonne R. Teems

USA

[‘No Longer Disabled’ - Reflections on a Transitional Process Between Disability and Aging in Switzerland](#).....p.122

Francesca Rickli

Switzerland

[The Becoming Subject of Dementia](#).....p.137

Katie Aubrecht and Janice Keefe

Canada

#### Notes From the Field

[Working Group: “ Reframing Interventions in Mathematics Education: Critical Perspectives”](#).....p.155

James Sheldon

USA

[Disability Studies Dissertation Abstracts](#).....p.155

## Editorial

### Old and Disabled - Disabled and Old

Megan A. Conway, Ph.D.  
RDS Editor

I was born old, or so I sometimes tell myself. Bad eyes. Bad ears. Bad hips. Creaky joints. When faced with people who don't seem to comprehend the meaning of the words, "Please speak up, I am hard of hearing," I find myself explaining, "It's just like with your grandmother. Pretend I am your hard of hearing grandmother and you'll be fine." "Ooooooh," the light dawns and, yes, they do speak louder, and also treat me like I am feeble minded. You know. Old.

A generation of once boogying Baby Boomers is getting old and they don't want the music to stop. The little reading glasses are popping out of pockets with an apologetic cough and a dismissive, "You know how it is." Advertisements are everywhere for "invisible hearing aids" with photos of smiling sort of older looking people playing golf or laughing with their sort of older looking spouse over a bottle of wine. Don't call it a "disability" because it can be fixed. I wish I could go back to school and become an orthopedic surgeon specializing in hip replacement surgery. Or plastic surgery. Or any field designed to make old people look/feel/act younger. Fund my active retirement, you know?

The irony of the anti-aging movement is that in some ways it has benefited people with disabilities. Those state-of-the-art hearing aids, large smart phone screens and "mainstream" surgeries benefit us too. But in other ways this movement has hurt us deeply. The stigma of disability grows more pervasive by the day. Trying to forge an alliance with an older generation who spends its time running from the inevitable ravages of time seems fruitless. Our only hope is that the generation who gave us the Free Love movement and the Civil Rights movement will also give us the Love Your Age Movement. Let your grey hair flow and your hearing aids show...

But we are getting older too. People who have lived with a disability for years now find that age and its new crop of disabilities demand a new examination of their strategies for living and self-identity. As a born-disabled I am quite comfortable with my identity as a disabled person. You wouldn't have to pay me to get me to stand up in a crowded room and shout, "Disabled people rule!" But a couple of years ago my husband, god knows he regrets it now, took a photo of the top of my head because I wouldn't believe him when he told me my hair was going grey. Let us just say that a significant amount of our family's income is now going to a very expensive hair salon. No way am I going grey. That would make me look old.

## Editorial

### **Disability and Aging: International Perspectives**

Katie Aubrecht, PhD & Tamara Krawchenko, PhD

“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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## Research Articles

### **Aging and Disability: The Paradoxical Positions of the Chronological Life Course**

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**Abstract:** This paper explores aging and disability, problematizing the paradoxical tendency to separate and conflate these social locations in chronological understandings of the life course. Exploring how such thinking has shaped assumptions, responses, knowledge, policy and practice, we conclude with suggestions to reconsider disability across the life course and into late life.

**Keywords:** successful aging, structured dependency, legitimized identity

### **Introduction**

The experiences of older people and people with disabilities<sup>1</sup> are commonly understood to unfold through patterns, events, and transitions throughout the life course and into late life. Lives are also considered to take place against a backdrop of age-based markers, social or institutional boundaries, and social and cultural expectations that correspond with stages or periods of life. Heavily influenced by structural functionalist thinking, the standard model of the life course, views individuals as progressing through 'normative' notions or stages along a relatively linear structure, with life events occurring at particular times (e.g., childhood, adulthood, and late life).<sup>2</sup> Chronological age is at the heart of what counts as standard 'normal' development at generalized life stages, with such understandings configuring lives through a set of structures, institutions and expectations of the 'institutionalized life course' (see Dannefer & Settersten, 2010; Kohli, 2007, Mayer, 2004). As such, both our views of the life course, and the experiences that take

place within this frame, are heavily influenced by the expectations and norms of the frame itself. Yet while scholars have drawn attention to the shifting interpretations of the life course and ‘growing old’, there is less attention to how this happens at the intersections of aging and disability, or how this impacts groups positioned ‘outside’ institutionalized structures or dominant cultural frames (for exceptions see Minkler & Fadem, 2002; Priestley, 2003; Raymond & Grenier, 2013). Yet, it is precisely the complex relationship and differential positioning of disability and aging in the chronological life course and across institutionalized structures that create unique tensions where contemporary aging and the life course are concerned.

This article focuses on locations of age and disability as they are conceptualized in institutionalized models of the life course. First, we explore the paradox that exists when the intersections of aging and disability are set against the conceptualizations of normative, chronological models of aging and the life course. In particular, we grapple with the separation and conflation of aging and disability across the life course, and how this has influenced assumptions and responses to older people and people with disabilities. Second, we outline how the experiences and expectations of aging and disability have been structured and institutionalized across the life course and into late life. This includes how policies and practices, such as those organized around dependency, have shaped and impacted what we know or assume about aging and late life. We then turn to how contemporary debates around age, disability, and ‘success’ de-stabilize taken-for-granted assumptions in the context of population aging. The paper concludes with a call to reconsider the constructs, narratives, and responses across the life course and into late life. It outlines how reconsidered notions of bodies and experiences over time can expose the disjuncture between standard life course anchors and subjective experiences that are structured by a chronologization of the life course and institutionalized through policy and practice responses.

### **Age and Disability Across the Chronological Life Course**

If we consider conceptualizations 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 in the standard chronological model of the life course. Chronological age dominates understandings of the pathways through the life course. Organized around age and stage-based transitions, the base for experience in the standard life course is primarily linear, with aging generally articulated as a process that unfolds across the period of one’s life (Grenier, 2012; Hockey & James, 2003). Most challenging for considerations of late life is that aging is both a biological and a socio-cultural process that is primarily measured in chronological years for the individual, and lifespan or life expectancy, where populations are concerned. Yet, the socio-cultural meanings and interpretations also play a role in configuring aging and late life. Whether referring to biological limits of life (i.e., longevity), the age of eligibility for public services whereby ‘dependency’ is structured according to one’s position in

paid labor (i.e., ‘structured dependency’), or the cultural constructs of ‘third’ and ‘fourth age’ that are respectively defined around new leisure lifestyles and decline (Gilleard & Higgs 2000), aging is generally considered to refer to a particular period of life accompanied by normative age-based 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 both in the joining of age and impairment<sup>3</sup>, and a countercultural ethos of activity, productivity, and success that functions to reinforce the imperative of ‘staving off’ disability and decline (see Gullette, 2004; Katz, 2005; Minkler & Fadem, 2002).

In many ways, the position of disability challenges the dominant age and stage based conceptualization of the standard chronological life course. Where aging is considered to occur toward the end of life, impairment and disability are not confined to a particular period. Injury and disability can take place across the life course and are difficult to fix in time. Such trajectories exist alongside social structures, institutional practices, and cultural expectations, and as such, are often conceptually and practically positioned outside standardized notions of the life course. Where institutionalized structures are concerned, policies and practices (especially those rooted in structural functionalist approaches), tend to separate disability from the standard linear and chronological life course. In such models, people with disabilities move through (or not) the institutions of the life course that are structured by age, stage, and institution (e.g., school, family, work, retirement) (Hockey and James, 2003). Such understandings, organized around the binary of normal/abnormal in relation to the standard life course explain, in part, the distinctions that are made between impairment as a functional or physical limitation which affects a person's body (Burchardt, 2004) and disability as a feature of social, environmental, or attitudinal barriers that limit full community participation relative to able-bodied counterparts (Stone, 2013). Led by advocates of social models of disability, these differences draw attention to the medicalization of disability, and the need for rights, citizenship, and inclusion for people with disabilities (Bricher, 2000; Lang, 2001). They also, however, point to how historical trajectories rooted in social identities and identity-based claims shape responses to older people and people with disabilities in different ways. Such distinctions only scratch the surface of the paradoxes that exist between aging and disability across the life course and into late life.

What is striking with regards to aging and disability is that although separated throughout the life course, impairment, disability, and age become conflated in late life. This occurs through attention to the biological realities of aging (i.e., comorbidity and age-related impairment that occur as one ages), and the socio-cultural narratives of decline and dependency. While ‘successful aging’ and ‘leisure lifestyles’ have gained prominence over the last 10-15 years, both the models upon which theories of aging are built (e.g., continuity, activity, disengagement), and the cultural narratives that can be considered to shape responses to older people, are based on the idea of natural decline as one moves through the life course. This is similarly the case in institutional practices, where assessment and eligibility rely on impairment and loss of function.

In this context, age can be considered to alter the interpretation of disability—and vice versa—as one moves into late life (Grenier, 2012). This differential positioning, or ‘situatedness’ of age and disability across the life course, and the conflation of age, disability, and impairment in late life, thus holds important insights for understanding the tensions that exist. While everyone undergoes a process of aging, and many people acquire impairments in late life, impairment and disability are not necessarily a part of ‘growing old’ (Oldman, 2002). It is this idea – that aging could be disability free— that exposes a crucial problem in existing conceptualizations and approaches to aging, disability, and the life course.

The separation and conflation of age and disability that occurs through the chronological life course creates tensions and reinforces the exclusion of people with disabilities and older people in different ways. Whilst disability is separated as ‘abnormal’ throughout the life course, age and impairment become conflated as ‘normal’, or expected, in late life. One result is that impairment and living with a disability becomes ‘naturalized’ through age. This can be seen in both the social impetus of initiatives to design better cities and spaces in order to prepare for population aging, and the experiences of people who have aged with disabilities. In the latter, people with disabilities have articulated how their needs for meaningful participation are finally being recognized, at least rhetorically in the frameworks on aging (Raymond & Grenier, 2013). A second result is the reinforcement of a medicalized view of disability as impairment that is supported by practices that prioritize function and the body in late life (Albrecht, 1992; Smart, 2006). In fact, nearly all references to disability among older people (with the exception of people aging with disabilities) take place using the term impairment rather than disability.

A third result takes place in the realm of social identities and cultural narratives. Older people can express reluctance to cross the boundaries of identity and align with ‘the other’; a label frequently assigned to persons with disabilities who are considered ‘unable’ to live up to able-bodied established norms (Morris, 2001; Siebers, 2006). Older people may also resist the classification of ‘disabled’ (Oldman, 2002) and align themselves with ‘successful’ ‘disability-free’ trajectories in order to counter the negative implications of impairment in age (i.e., 4th age). Similarly, people aging with disabilities may position themselves outside the chronological categorization of ‘old’ in order to resist the narrative of decline. What is often unrecognized in theory and in practice, is how such identity-based responses are both a function, and representation of a chronologically configured life course and the pathways created by structured dependency. Where the two groups meet is both in the practical allocation of services related to ‘dependency’, and experiences of unequal access, and/or stigma—that may occur at the intersections of age and impairment (see Oldman, 2002). That is, they meet outside the peripheries of the standard chronological and institutionalized life course, where ‘they’, as ‘othered’ groups are relegated to a late life period of devaluation. The dominant focus on normative, time-based discourses related to age-based chronology and impairment, thus create and sustain the paradox of aging and disability. They also represent a significant challenge for

theory, policy and practice, especially in the context of population aging. We turn now to a discussion of how policy and practice responses shape aging and disability in later life.

### **Policy, Practice and the Configurations of Dependence**

A focus on structured responses draws attention to how the separation and conflation of aging and disability have an influence that extends beyond identity-based questions. Throughout the life course, policy frameworks and service structures shape responses to people with disabilities and older people. As outlined above, the institutionalized life course is characterized by the creation of policy that is heavily structured around chronological age and normative patterns. In many ways, policy discourses focused on disability share many similarities with those on aging, wherein the emphasis in both has been on the work-welfare divide of exemption from adult labor. Herein, the social categories of ‘disabled’ and ‘old’ are, at least in part, constructed and defined by their relationship to work and the economy through what is referred to as ‘structured dependency’ (Barnes, 1996; Oliver & Barnes, 2011; Phillipson, 2013). From this structured dependency perspective, aging and disability are produced as an economic problem – with older people and those with a disability being forced into situations of dependency because they do not participate fully in the processes of production. Structured responses thus create forms of exclusion that take place through relationships with work and biomedical interpretations of impairment throughout the life course and into late life.

That said, a good deal of variation exists in the structured responses to aging and disability. Here, medicalized interpretations of impairment and ‘disabled bodies’ inform approaches to ‘dependency’, setting forms of recognition, and defining eligibility for social programs in ways that sustain the separation and conflation of disability and aging. Standard life course models rooted in chronological age position age as primarily indisputable based on date of birth. Yet, the status of ‘disability’, especially as contested eligibility, can be considered to 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 (Chouinard & Crooks, 2005; Lightman et al, 2009). Policy and services thus structure ‘dependency’, reinforce the importance of a ‘disabled identity’ in rights and service claims, as well as shape cultural interpretations or expectations. At the same time, medical definitions and classifications on the body are reintroduced in late life by means of standard assessments of functional limitations or ‘frailty’ in order to qualify for public services (Grenier, 2007). Where age provides access to the universal programs of income support (e.g., retirement), thereby altering interpretations of ‘dependency’, it is impairment that provides access to health and social services for older people, and disability that provides access to compensation for people with disabilities who are ‘not yet old’.

Major differences exist between how persons who have ‘acquired disability in later life’ and persons ‘aging with a disability’ fit into the institutionalized frameworks and constructs of late life. Persons who have aged with a disability are often considered ‘disabled’ (including self-identification), with persons who have acquired impairments in late life labelled as ‘impaired’ or ‘elderly’ (Jonson & Larsson, 2009). Impairment and diagnosis are used to distinguish between individuals and channel eligibility for services, with such processes marking recognition, and the boundaries of inclusion/exclusion. Jonson & Larsson (2009) argue that the chronologization of the life course is divided into three stages: education, work, and life after retirement. So, while the trajectories of some people with disabilities take place within the educational system or labour force, and thus within the boundaries of the institutionalized life course, others have trajectories of specialized education or receive social benefits outside of work (i.e., income support) that flag their dependence, and position them outside the life course<sup>4</sup>. Such conceptualizations create insider/outsider boundaries, and reinforce the importance of rights and identity based claims. This is especially the case where a ‘disabled’, or ‘frail’ identity or classification provides access to programs or services. 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 re-entry where disability and impairment become conflated in late life.

Considering structured responses in late life draws our attention to a shift that occurs as people with disabilities move into late life, and whereby disability and aging become conflated. At the practical level, the shift occurs as people with disabilities move from income support programs based on disability to those based on chronological age (i.e., pension). Where the transition between such programs can result in changes in income or medical coverage, they also signify a fusion of disability and age where the standard chronological life course is concerned. People with lifelong disabilities, or those that occur before the age of retirement (roughly 65), move into a period characterized by tensions between age-based ‘rights’ and ‘decline’. Yet, while the processes may be considered a mere transition in the broader ‘institutionalized life course’, the implications for identity, meaning, and response, are substantial. Age, and the associated process of defining of older people as ‘old’ rather than ‘disabled’ begins to alter eligibility for programs and services relative to younger counterparts (Jonson & Larsson, 2009). Where in some ways, this transitional point expands access (i.e., entitlements become universal in the case of pension), in others, access (or benefits) may be reduced under assumptions that normalize impairment and decline in late life. This turning point in the configuration of ‘structured dependency’, and its associated socio-cultural implications as one moves through the life course offers insight into the paradox of disability and aging. In particular, how differential responses organized around age can serve to structure inequality and conflate disability and



aging in ways that are problematic for both groups. Walker and Walker (1998) for example, claim that there has been a “longstanding preference on the part of policy makers to draw a line between older and younger disabled people on the grounds that disability in older age is a ‘natural’ part of the ageing process ...that absolves the responsibility of taking action to recognize the needs of older disabled people” (p. 126). Where such processes can obscure the different needs that may exist, they also draw attention to how the normalization of ‘age-based’ impairment can justify overlooking older people’s needs, especially when set against the cultural imperative of successful aging. In this case, a transition often depicted as new or different has mutually reinforcing consequences where disability and late life are concerned.

The impacts of variations in structured dependency are most obvious in the example of retirement. Initially configured as a right and form of social protection for older people, retirement offered a reward for a life-time of contribution. In this case, a form of legitimacy accompanies ‘dependence’ in late life, via links to workforce participation. The protection, both in terms of economic benefits and status, is deeply rooted in the participation in the ‘normative’ and standard institutionalized life course. This raises two challenges for older people and people with disabilities. First, while universal, and thus offering recognition, the protections offered have the greatest benefit to groups who have held a lifelong connection to the work force. In current systems, there is differential access to the rewards of social protection, wherein groups such as older women and people with disabilities with lower levels of life course work force participation have less access to both the material resources (work force contributions structure pension benefits), and thus, the associated ‘deservedness’ that is associated with connections to the labour market. Separation from standard institutions produces trajectories of inequality that become deeply apparent as one moves through the life course. Late life poverty, and the associated stigma or exclusion, is therefore not only systemic, but unequally distributed. The second related issue is that shifting institutionalized frameworks, such as measures to raise the age of eligibility for public pension will pose the most significant challenges for older people who have had less stable (or non-existent) ties to work. This includes large numbers of people with disabilities who may have experienced discrimination in terms of accessing employment, persons unable to work for health reasons, and groups of older people who have left the workforce earlier than retirement as a result of illness or injury. So, while retirement can be seen in some ways to offer a ‘legitimized identity’ in later life, it is only partially available where disability is concerned.

The differential structuring of dependency that occurs in relation to the institution of work 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 to aging and late life (see Phillipson, 2013). Attempts to alter frameworks and programs that structure dependency through inclusion of people with disabilities in the educational system and retirement, will thereby create new challenges where aging and disability are concerned

(Priestley, 2003). Initiatives 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. While the discourse of participation resonates with longstanding advocacy for access, inclusion, and normalcy (Priestley, 2003), the impacts will depend on whether this access is rhetorical, or meaningful, as well as whether it proves capable of altering the systemic exclusion that currently occurs (Raymond & Grenier, 2013). Frameworks of participation, if enacted in line with the experiences of people with disabilities, hold the potential to challenge the separation from the life course, and subsequent accumulation of inequalities. Yet, to what extent are these measures concealed efforts to ‘get everyone to work’ and reduce spending and forms of social protection in the context of increased longevity and population aging? And further, how will this merger of ‘dependent’ groups that occurs through work and ‘extended work lives’ play out in late life, where the backdrop for aging is one of a ‘success’ that is disability free?

### **The Contemporary Focus on Success and the Potential Future of Life Course Policy**

Over the last 20 years, the negative interpretations of aging as ‘dependency’ have shifted dramatically to include a potential that is organized around ‘success’. Positive aging discourses such as ‘active’, ‘successful aging’, ‘productive’, or ‘healthy’ aging, were coined as a challenge to the construction of aging as a period of decline and dependency that were dominant since the late 1960s (Katz, 2001-2002). The idea was that aging did not need to be considered a negative period of life, but one that held promise. However, frameworks of ‘success’ have proven contradictory where questions of health or disability position particular groups outside the boundaries of ‘success’ (Asquith, 2009; Lewis, 2013; Mendes, 2013; Raymond & Grenier, 2013). The contemporary focus on ‘success’ in guiding frameworks on aging for example, means that disability in later life is often framed as a matter of failed personal responsibility (Laliberte Rudman, 2006; Martinson & Minkler, 2006) and an example of ‘failed aging’ (Boudiny, 2013). The problem is that as positive aging discourses, including the widely-known ‘successful aging’ paradigm proposed by Rowe and Kahn (1997), prioritized good health, independence, continued engagement, and social connectedness (Asquith, 2009), it also drew a crucial boundary between health and illness in late life, and relegated ‘disabled bodies’ to ‘unsuccessful aging’, and ‘the fourth age’ (Grenier, 2012). This rift between healthy and ‘ill/impaired bodies’ solidified through the narrative of ‘success’ became the dominant model for aging and late life. The unintended result was, and is in many ways, a return to the normal/abnormal positions embedded in the conceptualization of the standard chronological life course.

Although disability across the life course has not been organized according to this expected frame of ‘success’, what is problematic where disability and age is concerned is how ‘successful aging’ leaves no space within which to meaningfully articulate experiences of aging that are accompanied by impairment. In this case, it is not simply that impaired bodies, or impaired older

bodies, are positioned outside the norm, but that the key framework from which to confront negative interpretations of aging as dependence and decline, age-based discrimination, and the accompanying stigma, is rooted in the avoidance of disability in late life. That is, 'freedom' from the negative valuations of age, is only possible by avoiding illness, impairment, and disease. In her work *Feminist, Queer, Crip*, Kafer (2013) frames this problem as the 'curative imaginary' where the idea of a future can only be conceived through purging or solving disability. As such, older people with impairments become located outside both the standard and the ideal, when late life 'success' is defined as disability/impairment free, or at least, to be approached with the minimal impairment possible. Too much disability and need for assistance (e.g., cane, wheelchair, etc) quickly tips the older person into aging by means of impairment, and thus, the antithesis of 'success'. Yet, contradictions emerge at the locations of lifelong disability and the strategies used to support activity and social engagement. Although on one hand, lifelong disability can serve to de-stabilize the coupling of age and impairment by means of rendering difficult the answer to 'when does one become old?', the emphasis on success as the absence of 'impairment' reinforces the paradox of aging and disability. The conflation of impairment, disability, and aging, as operationalized through standard models of aging, and reinforced through frames of 'success', thereby creates an impossible target for older people with disabilities who, in turn, may be marginalized, receive fewer opportunities for meaningful social engagement, and subsequently be excluded from mainstream society (Laliberte Rudman, 2006; Mendes, 2013). It is also problematic to the extent that it privileges lower levels of disabilities and operates as part of a powerful illusion that a disability free life can be achieved in late life. So, while people with disabilities can conceptually be considered to re-enter the standardized life course in later life, they do so at a location that is problematic and discriminatory, whereby the idea of disability as 'tragedy' is reinforced through the dominant narrative of success=a disability-free life.

Similar issues are present within various ideologies, policy constructions and practices that justify the systematic oppression of those living with disability (Barnes, 2005). From an international perspective, most disability policies remain rooted in a narrow medical model (Horejes & Lauderdale, 2014) – wherein the very label of 'disabled' is an attempt to categorize those who have failed to meet the expectations of ability (Greco & Vincent, 2011). Here, sociocultural expectations of 'normalcy' are established and given meaning in a context which privileges and projects 'able-bodied' values (Fitch, 2002; Terzi, 2004)—a focus that McRuer (2006) (drawing on Butler), terms 'compulsory able-bodiedness'. Demonstrating parallels with discourses of successful aging, people with disabilities are often evaluated and categorized at the individual level in relation to their degree of dependence, with these assessments forming the basis for recognition and often times, service response (Fine & Glendinning, 2005). The social model of disability was a deliberate attempt to shift attention away from the functional limitations of individuals with impairments onto the problems caused by disabling environments,

barriers and cultures (Priestley, 2003). Social model rhetoric, if not policy, is now clearly evident in the publications of a host of agencies dealing with disability and related issues in both the statutory and voluntary sectors (Barnes & Mercer, 2010; Shakespeare, 2006). Yet, as Barnes (2012) points out, these policies have had only a marginal impact on the growing numbers of people labelled 'disabled' in both rich and poor countries alike.

Recent work in disability studies has turned to the importance of 'reconfiguring and imagining spaces in ways that can include the widest array of bodies and minds' (McRuer, 2006; Kafer, 2013). Concepts of 'crip futurity' (McRuer, 2006) and 'feminist queer crip' (Kafer, 2013) for example, question current constructs, practices, and envision shared/sustainable futures, and are in line with the critique we offer through this paper. Tackling ideas about disability, Kafer (2013) outlines how the configuration of disability as 'tragedy' and the absence of a future, or 'what ends one's future' (p.3) is a major part of the problem. It is precisely this interpretation – combined with devaluations of age—that portray impairment in age as a negative state. Although currently representing a small body of literature, perspectives on 'crip futurity' have evolved from postmodern conceptualizations that position disability as a more fluid, dynamic, and less descriptively-defined concept (Carling-Jenkins, 2014; Meekosha & Shuttleworth, 2009). Interpretations of fluidity in disability studies for example, have outlined the importance of articulating the contextual nature of identity formations and transformations, as well as changing micro-macro social relations and cultural meanings (Meekosha & Shuttleworth, 2009). The focus on fluidity has also drawn attention to the inherent challenges of the social model, in particular, how insistence on the removal of barriers may be unrealistic (Shakespeare, 2006; Shakespeare & Watson, 2001; Tremain, 2002), as well as how approaches to date may have excluded important dimensions of people's experience (Barnes, 2012; Shakespeare & Watson, 1997). 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. For our purposes, 'feminist queer crip' and/or 'crip futurity' may provide the theoretical frame to uncouple lives from the current limits of the standard normative chronological life course.

Our attempt in this paper has been to bring understandings of work on disability and aging in closer discussion, in order to consider the intersections and contradictions. What it has produced is a clear need to reconsider categories, relationships embedded in policies and practices, and the need to develop an inclusive and sustainable vision for the future. The paradox of disability and aging and the implication of 'tragedy' and 'failure', draw attention to the need to more fully investigate the relationship between policy structures and lived experience. Particularly needed are approaches that detail how trajectories of disadvantage can lead to inequalities across the life course and into late life. Such understandings outline how age, and 'aging' as attributed by means of ill-health and impairment, is not only a function of chronological age, but may occur 'prematurely' as a result of access and/or structures of disadvantage. There are countless examples where the presence of multiple impairments (often

referred to as comorbidities) result in what is often labelled ‘premature aging’ as a result of disadvantage (e.g., homelessness and aging; Indigenous aging). Important in their own right as social issues, such illustrations draw attention to the very problem we are trying to address—the idea that late life impairment is interpreted as ‘aging’, irrespective of the ways in which lives were configured by social conditions (e.g., poverty, poor housing, water/sanitation, colonial practices, and so forth). It is this challenge of balancing ‘needless’ impairment as a result of disadvantage, with the valuing of disabled lives that will pre-occupy our future. This issue of understanding and responding to age and disability in meaningful ways can be expected to intensify in the coming years.

Population aging represents a unique context characterized by greater numbers of older people (‘greying societies’), increased longevity (longer lifespans overall, including groups who have historically lived shorter lives), and lives that may be spent with more years of chronic conditions or impairments (as a feature of longevity and biological aging, disadvantage, but also as a result of medical and technological advancements). What this means is that impairment and disability are likely to become more prominent features of our so-called ‘greying societies’, and will likely prompt (if only by sheer volume of people) a reconsideration of disability, as well as a reconfiguration of public space. As such, it is entirely possible that the illusion of ‘success’ as it is currently configured may shift or become exposed for what it is—an illusion. In this context, the stakes are high for reconfiguring and imagining a more habitable world (Kafer, 2013). Population aging and the future thus underscore the need to grapple with the tensions between disability and aging, and create spaces where older people with disabilities (lifelong or acquired) can see themselves in frameworks, and live out their later years without the stigma of being defined as ‘unsuccessful’.

One suggestion to move away from the fixed age-based responses is to draw on life course approaches as a policy lens—that is, to develop what may be referred to as a life course policy (McDaniel & Bernard, 2011; Priestley, 2003; Settersten, 2003). According to McDaniel and Bernard (2011), the idea is that principles of the life course perspective<sup>5</sup> can open new possibilities for policy interventions across institutions such as education, labor and employment, family policy, health care and social assistance. Although life course policy remains underdeveloped at this point, the suggestion is that trajectories, patterns, and relationships—when configured as more than individual trajectories—may hold potential for targeting responses across the life course and into late life. In this vein, life course policy may offer a flexible frame that highlights trajectories of disadvantage and inequity, and works across complex social and policy environments to ‘bring disadvantaged groups into being an advantaged group’ (McDaniel & Bernard, 2011, p.S10). In the case of aging and disability, it may shift the focus from chronological notions of age and stage and the problematic currents of ‘normalcy’. However, there is also the challenge of replicating existing age-based assumptions that are embedded in the institutionalized life course, and the reality that life course policy may

offer little in terms of altering socio-cultural associations such as those of late life ‘impairment as decline’, and ‘disability as tragedy’. If life course policy is to become a useful approach, it will require a detachment from chronological approaches to the life course, and the paradoxical relationship between disability and aging. Here, we suggest that the development of life course policy as a potential solution engage in two considerations: First, ensuring that the approach balances views of inequality with reconfigured relations of access and inclusion. Second, that responses developed from this lens recognize and support ‘disabled and older lives’, rather than positioning them as ‘tragedy’ or ‘failure’. Further, perspectives must provide the space to articulate meaningful interpretations and experiences at locations of disability and age. It is here that we suggest that the future versions of life course policy be grounded in Kafer’s (2013) utopian vision of a sustainable future that provides a basis for reimagining individual identities, social justice, and shared futures.

### Conclusion

The constructs, frameworks, and responses to disability and impairment across the life course and into late life require review. This rethinking will aid in re-conceptualizing a late life with disability that is not inevitably a ‘tragedy’, and devoid of ‘future’, but mindful of wide-ranging realities (see Kafer, 2013). We argue that a good proportion of the problem lies in our reliance on standard institutional life course models and approaches that are rooted in age-based models of the life course, and interpretations of impairment as inherently negative. Even approaches that have attempted to remove barriers of age remain heavily structured around chronological age via a link to either structured dependency or impairment as a negative experience. This is characterized by the tendency to separate or position disability outside the ‘frame’ of the life in earlier periods of the life course, yet to re-introduce and conflate impairment in aging as a central feature as one progresses in chronological age and into the upper extremes of the life course – an intersection of the ‘decline’ and ‘tragedy’ narratives. A view of life experience as more fluid and permeable across time may be the first step in recognizing the complexity of the interrelationship between disability and age, and loosen the current bind of approaches to impairment, disability, and late life. Here, we suggest that linking the body of scholarship on fluidity in disability studies and gerontology may be particularly fruitful, and that the notion of futurity in particular, may help to resolve the current paradox.

Further, we have argued that the separation of disability and aging from the life course, and the conflation of aging and impairment, create a paradox in the contemporary context that is overwhelmingly dominated by individual and active interpretations of ‘success’ and ‘failure’. Extant critical approaches have tended to focus on either disability or aging, yet contemporary contexts call for more nuanced understandings of the relationship between aging and disability across the life course and into late life. We acknowledge that fixed frameworks based on chronological age and the standardized life course may well have reached their limit. However,

at the same time, there is a void from which to define experiences that incorporate aging, impairment, and disability. Where a refined version of the life course may hold potential, current interpretations, in particular those that rely on individual trajectories may fall short of the rethinking that is required. Such an approach may be problematic for example, where experiences at particular social locations and/or identities butt up against current practices of recognition and/or eligibility for public services (e.g., the expectation of frailty or a particular diagnosis of 'risk'). Our suggestion is to reconsider aging, impairment and disability from critical perspectives of the life course that account for the interplay of power within and between structures, systems, contexts (including the socio-cultural), relationships, and lived experiences. This may include linking critical studies of aging with notions such as those outlined in Kafer's (2013) perspective of 'feminist, queer, crip'.

Rethinking and reconfiguring responses to aging/impairment and disability/aging will require an approach that is capable of considering personal, social, political, and cultural expectations of disability and aging that can inform research, policy, and practice for future aging societies. The differences and alternate pathways across the life course and into aging can provide insight into the disjuncture that exists between dominant age and stage-based approaches rooted in linear time, the suggested models organized around binary models of independence/dependence and success/failure, and the subjective needs and experiences of older people and people with disabilities. One of the most significant challenges for the future will be in addressing both the exclusionary practices and the normative assumptions that continue to shape responses and experiences of disability, impairment, aging and late life, and in configuring spaces of meaningful involvement. We urge research, policy and practice to work closely with older people and people with disabilities to discover suggestions and solutions to the existing paradox. It is only through ventures that link these voices, accompanied by insights from disability studies and the critical perspectives of aging and late life, that we can move forward in creating understandings and future visions where the needs of older people with lifelong and acquired impairments can be meaningfully included in the social and cultural spaces of a re-envisioned and inclusive life course.

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### Endnotes

<sup>1</sup> Throughout the paper we use first-person language of older people and persons with disabilities as a means to recognize the person and their experiences. We also use the term disability when referring to disabilities across the life course, and persons aging with disabilities when speaking of a population group. We recognize the challenge that exists in the language (especially when moving across fields such as critical gerontology and disability studies), and that leading advocacy work has used the language of 'disabled persons' as a means to shift responsibility from the individual to society (Morris, 2001). An interesting discussion on the language used in disability studies can be found in Kafer's (2013) work on feminist queer crip, where 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 (see p 4).

<sup>2</sup> See Hockey and James (2003) for a critique of the standard model of the life course.

<sup>3</sup> We use the term impairment throughout with regards to the practices of assessment and framing of disability in late life. In late life, the dominant use of impairment is related to bio-medically framed assessment practices that take place with regards to older bodies and care. Our intent in using this term is to draw attention to the differences that exist in the language used in earlier and later periods of late life, and to problematize how this language structures and shapes experiences across the life course and into late life. This distinction is part of the paradox.

<sup>4</sup> The use of other in the structure is intentional here, to denote how othering occurs through this process, and results in a separation from the life course.

<sup>5</sup> McDaniel and Bernard (2011) outline "The life course consists of four basic principles: 1) that our daily experiences form a trajectory that begin at birth and stretches to death; 2) that life-course patterns unfold in a multiplicity of interconnected realms; 3) that social bonds for throughout our lives that affect our life course and that of others; and 4) that a variety of local and national contexts shape life courses, and are shaped by them" (S2).

## Research Articles

### Securing Personal Input from Individuals Aging with Intellectual Disability: Do Differing Methodologies Produce Equivalent Information?

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**Abstract:** Research is limited on whether differing methodologies for facilitating personal contributions from individuals aging with intellectual disability produce equivalent knowledge outcomes. Two matched purpose-developed tools examined five quality-of-life domains. Results showed substantial variance between qualitative interview responses and Likert-scale data, and indicate validity concerns for using either methodology in isolation.

**Keywords:** aging, intellectual disability , likert-scales, qualitative interviews

### Introduction

The life expectancy of people with intellectual disabilities has undergone a remarkable Determining Quality of Life and Life Satisfaction increase in recent decades (Coppus, 2013). However, it has long been recognized that the mere extension of life does not necessarily result in a high quality of life as people age (Brown, 1993). This understanding has resulted in an increased focus on supporting active, positive, or successful aging (Boudiny, 2013). One of the current issues facing both the disability and aged care sectors is the relative scarcity of research data regarding the ongoing desires and expectations of individuals with intellectual disability about their lives and gathered directly from them (Bigby et al., 2014; Nind, 2011), and particularly as they age (Parmenter et al., 2013; Wark et al, 2013a). This lack of knowledge in turn results in difficulties for family members, service providers and public sector administrators in identifying societal or other structural impediments (Wark et al, 2014a), and understanding how to best meet the needs of this cohort of people (Cummins, 1997; Wark et al., 2013b, 2014b).

There remains a significant question concerning the best mechanisms that can be used to gain the direct and accurate input of people with intellectual disabilities. This situation is particularly relevant for individuals with more severe intellectual impairment and / or significant communication difficulties (Boland et al., 2008; Walmsley, 2001). It is highly pertinent in light of Australia's current national disability reforms which specifically nominate the need to ensure the contribution of all individuals with the disability in any decisions about their life (Bonyhady, 2014).

### **Determining Quality of Life and Life Satisfaction**

One of the main methodologies for assessing an individual's level of satisfaction with their life has been to use a quality of life (QoL) measure, with a number of validated scales focusing on specific population sub-groups (e.g., Perales et al., 2013; Makai et al., 2014). QoL has become one of the major measures of disability organisations with the framework used for evaluating the appropriateness of services and their delivery mechanisms (Kober & Eggleton, 2009). The research literature would appear to support the concept of QoL measurement having to occur through a variety of different qualitative and quantitative indicators, but it is also recognized that these dimensions will vary both across time and individuals (Chun Yu et al., 1996; Emerson et al., 2013; Felce & Perry, 1997).

Quantitative indicators are useful in providing a summary of general achievements against pre-determined goals, with Likert-type scales often utilized to quantify an individual's levels of satisfaction (e.g. Cummins & Lau, 2010). However, adequate inclusion of appropriate qualitative indicators is also recommended as this mechanism directly involves people with disabilities in the assessment process (Cummins, 1997). Alternative options, including seeking the input from proxy respondents such as carers rather than the actual person, have been shown to be potentially unreliable (Stancliffe, 1995). So while it is acknowledged that not all people with an intellectual disability may be able to self-report (Finlay & Lyons, 2001), facilitating the direct involvement of the individual is desirable whenever possible. The issue of how to best assess perceptions of individuals with an intellectual disability as they age with respect to their lifestyle still remains, as there is little agreement on a precise definition of QoL for this cohort, how to measure it, or even what factors are most appropriate to assess (Wark, 2011).

### **Comparing Outcome Data for People with Intellectual Disability**

Concerns about the reliability of information gained from a proxy-respondent, when compared to self-reports, support the wider movement towards greater involvement of individuals with intellectual disability in making decisions about their life (Emerson et al., 2013). Two of the main approaches for gaining a direct contribution from people with intellectual disabilities are semi-structured qualitative methodologies utilizing interviews and structured quantitative methodologies using Likert-type rating scales (Beail & Williams, 2014; Brown et

al., 2009; Sigstad, 2014). Likert-type scales, often modified to include pictorial aids, such as smiley face emoticons (Schmidt et al., 2010), are commonly used with people with intellectual disabilities, and particularly among those with communication difficulties. While Likert-type scales can provide a complementary tool to support input from people with intellectual disabilities, in some scenarios they are used in isolation as an alternative for individuals who may not be otherwise able to verbally contribute their opinion in an interview situation (Hartley & MacLean, 2006). In Australia the Commonwealth Government specifically recommends the use of alternative communication strategies and methods in order to facilitate the direct involvement of individuals with intellectual disability (Department of Social Services, 2014a); however, this approach contains an inherent assumption that the information from all such methods provide equivalent knowledge. If the goal of using alternative communication tools, such as Likert-type scales, is to facilitate the involvement of people with intellectual disabilities in making decisions about their lives (Ottmann & Crosbie, 2012), it remains unclear whether the information gathered from a qualitative interview and a quantitative Likert-scale is directly comparable.

This issue is highly relevant in Australia currently due to major legislative changes, including the National Disability Insurance Scheme (Commonwealth Government of Australia, 2013; Parmenter, 2014), individualized funding, and person-centered approaches (Ageing Disability and Home Care, 2013). A key aspect of these reforms is a strong focus on gaining the direct views of all individuals, particularly the person with a disability, through the use of any relevant tools necessarily to gain this input (National Disability Insurance Agency, 2014). This approach involves carers, health professionals, and advocates determining life aspirations and assessing quality of life in collaboration with individuals with intellectual disability. In practice, it may result in a situation where some people are interviewed using open-ended qualitative methodologies about their thoughts or opinions, while others participate through completion of a pre-determined quantitative tool using a Likert-type scale. This presents a major equity problem; if there is no level of equivalency of information gained through responses from either a Likert-type tool or a personal interview, one cohort may be disadvantaged as their opinions and desires may be identified incompletely or incorrectly.

### **Current Study**

The goal of the current pilot project was to use two matched and purpose-developed tools, a semi-structured qualitative interview and a structured Likert-type quantitative scale, to examine the perspectives of individuals aging with an intellectual disability regarding their quality of life. This paper examines part of the cross-sectional data gained from a cohort of participants who completed both tools during the one session. The results from 20 participants are compared to determine if there were similarities in the response patterns and if any conclusions can be drawn about the equivalency of the two methodologies.

## Methodology

### Recruitment

A request for expressions of interest and an information package regarding the study was sent to disability and aged care agencies in major metropolitan (Sydney, Wollongong, Brisbane and the Sunshine Coast) and rural (Toowoomba and Parkes) locations across New South Wales and Queensland in Australia. The study specified that participants needed to be older adults with an intellectual disability; no precise definition of 'older' was provided due to the inherent variability in the sample, but a nominal minimum age of 55 was suggested.

On-site information sessions for potential participants, carers, support staff, families and advocates/guardians (where applicable) were held which explained the goals of the project. Participants then self-nominated to the researchers, with both written and verbal informed consent being gained from each individual prior to commencement. Individuals had to be capable of participating both in a face-to-face interview and to respond to survey questions, although assistance was provided to overcome any issues with literacy. Formal ethics approval was provided by Institutional Ethics Committee (institutional name and ethics approval number to be provided after blind review).

### Participants

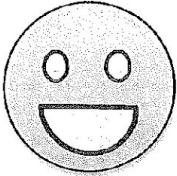
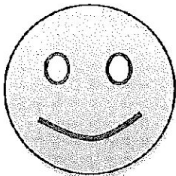
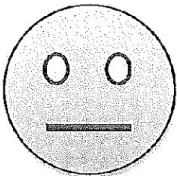

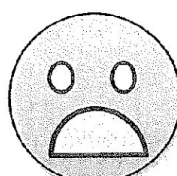
This paper reports on 20 sequential qualitative interviews and 20 quantitative Likert-type scale scores from the same individuals. Each participant in the study had to be able to give informed consent to participate in the research. Consent was determined initially by the participant in line with the protocol of the New South Wales Government (Attorney General's Department, 2008), but also verified by the support organisation and/or person responsible. One individual indicated a strong desire to participate, however, it was agreed by the organisation and interviewer that they were not capable of providing informed consent. The decision was made to still 'interview' the person as a number of their peers were involved and they did not wish to be 'left out', however the person's data was not recorded or included.

The 20 participants were split evenly between New South Wales and Queensland (10 from each state); however there were more males than females (12 to 8) and slightly more rural than metropolitan area residents (11 to 9). The average age of all participants was not able to be definitively collated, as it was apparent in some cases that the age provided by the participants was not chronologically feasible (i.e., four interviewees volunteered ages that were inconsistent or impossible, and/or they could not provide a precise date of birth). Attempts were made to confirm all ages with family or carers, but accurate data was simply not available for two

participants. Of the ages that could be verified, the range was from 52 to 79 years with a mean of 60 years.

**Tools**

The participants were interviewed using a semi-structured format and were also asked to complete a hard copy of a five-point Likert-type scale featuring both written and pictorial (smiley faces) prompts. The Likert-style scales used a simple 1=very happy through to 5=very unhappy delineation. A sample of the Likert-scale with its associated pictorial aid is included as Figure 1.

1	2	3	4	5
				
Very happy	Happy	Not happy or unhappy	Unhappy	Very unhappy

**Figure 1 – Likert-Scale**

The interview featured semi-structured questions relating to key domains of ‘residence’, ‘support’, ‘health’, ‘changes in health associated with aging’, and ‘life satisfaction’. The interview data were captured through audio-taping with independent transcription. Each participant was also asked to use a five-point Likert-style scale to rate five questions that related to the key domains explored in the interviews:

- “How happy are you living where you live?” (Residence),
- “How happy/satisfied are you that the help you receive?” (Support),
- “How is your health?” (Health),
- “How has your health changed as you’ve gotten older?” (Changes in Health), and
- “How happy/satisfied are you with your life today?” (Life Satisfaction).

While it is recommended to assess acquiescent responding of participants in Likert-scales through the inclusion of specific neutral or negative questions (e.g. Cuskelly, Moni, Lloyd & Jobling, 2013), this was deliberately not included in this project for two reasons. Firstly, the



purpose of the current research was to examine the similarity of data gained from individuals aging with intellectual disability through differing methodologies, and how these results relate to real world practice. It was not considered likely that all studies would follow the recommended acquiescence protocol, and therefore it was not appropriate to do so in this project in order to best replicate potential real-world scenarios. This issue was felt to be particularly relevant for disability or aged-care organizations seeking the personal contribution of service-users, rather than more highly structured academic research projects. It was also believed that, due to the short nature of the tool and the very specific alignment of five questions to the five quality of life domains, the inclusion of any additional items could be potentially confusing to participants.

### **Coding of Interview Data**

All 20 interview transcripts were individually coded by two members of the team according to whether each separate statement was positive or negative in terms of the individual's experience, and then categorized into the nominated five domains. Statements could be coded multiple times, with both positive and negative components within the one statement (e.g. "My health problems are much worse now [coded as negative], but my support staff are excellent" [coded as positive]). Statements that were neutral, ambiguous, or unrelated to the interview question ("e.g. "look at that dog over there") were not included in the analysis. Any disagreements were resolved through discussion. The first three interviews were separately coded by an independent third person to ensure the overall ratios of positive and negative statements were the same.

Initial consideration was made for also coding the 'intensity' of the statements, however this proved to be impractical. Attempting to objectively quantify the underlying positive or negative strength of each statement within a cohort of geographically dispersed individuals aging with intellectual disability was not considered feasible. A high level of familiarity with each participant was deemed necessary to accurately distinguish emotional engagement with the content from other personal and environmental factors. As an example, a number of individuals spoke with a uniform neutral tone throughout the interview, and any attempt to categorize the intensity of their different responses was considered to be highly subjective and liable to substantial inter-rater variance.

## **Results**

### **Interviews**

There was an average of 63.9 statements per interview that were coded as either positive or negative, with a range of 11 to 193. There were an average 38.1 positive statements and 25.8 negative statements per interview, which represented a ratio of approximately 1.48 times as many positive statements as negative.

An estimate of the overall ‘positivity’ of each interview was calculated by comparing the number of positive statements against the number of negative statements. A number below 1 indicated that the interview was skewed towards the negative, while a number above 1 indicated a positive result. Table 1 presents the breakdown of the positive versus negative statements within each interview, and the overall positivity score for each individual’s interview.

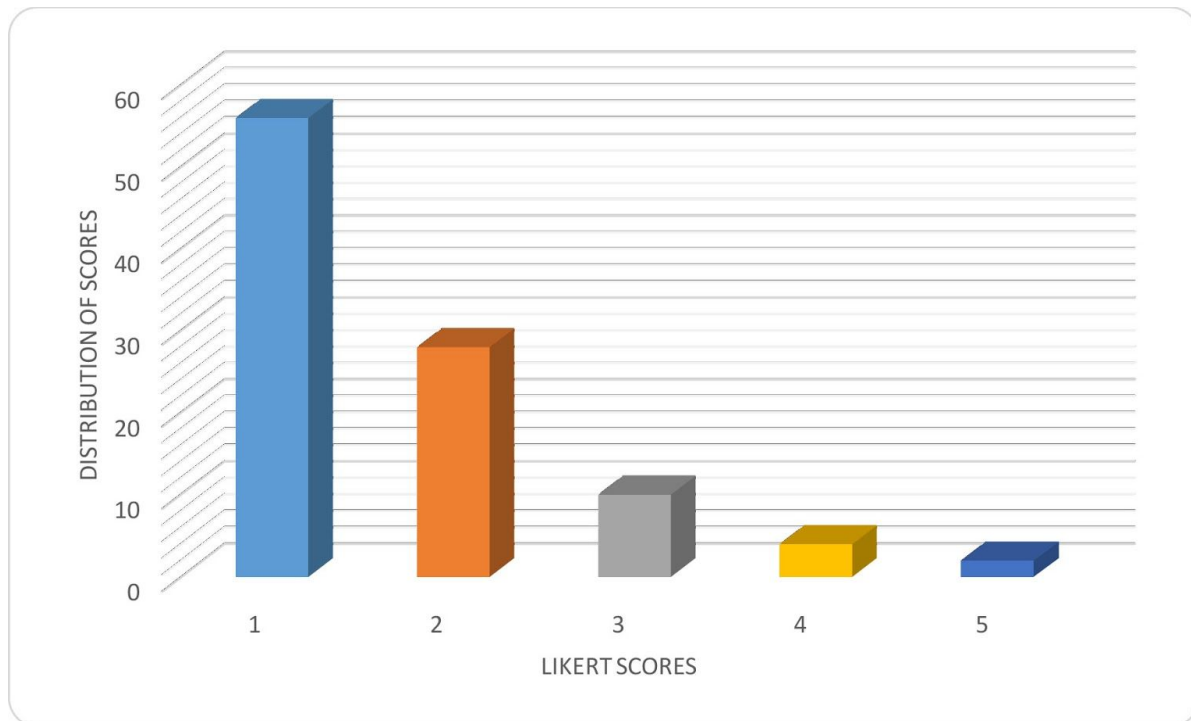
**Table 1 - Overall Positivity of Interviews**

Interview Number	Interviews		
	<i>Positive Statements</i>	<i>Negative Statements</i>	<i>Overall Positivity</i>
1	30	33	0.91
2	35	30	1.17
3	108	85	1.27
4	30	18	1.67
5	45	31	1.45
6	6	5	1.20
7	30	16	1.88
8	80	27	2.96
9	65	72	0.90
10	39	23	1.70
11	36	13	2.77
12	17	5	3.40
13	29	20	1.45
14	29	27	1.07
15	26	17	1.53
16	25	3	8.33
17	29	33	0.88
18	23	23	1.00
19	56	14	4.00
20	24	20	1.20

### Likert Scores

Of the 100 distinct Likert scores (20 different participant scores across the five scales), only six were rated as being lower than the neutral position. There were 10 neutral scores, with the remaining 84 scores all either being positive (28) or very positive (56). This shows a very strong

trend towards the ‘very positive’ end of the scale (mean score 1.6). These data are represented in Figure 2 below.



**Figure 2 Distribution of Likert Scale Scores**

Alternative text description – The image depicts a bar chart of the y-axis is labeled Distribution of Scores ranging from 0 to 60 and the x-axis is labeled Likert Scores with 1, 2, 3, 4, and 5. The results of the likert score for 1 has a distribution score is 54; likert score for 2 has a distribution score is 28; likert score for 3 has a distribution score of ~8; likert score for 4 has a distribution score of ~2; and the likert score for 5 has a distribution score of ~less than 0.

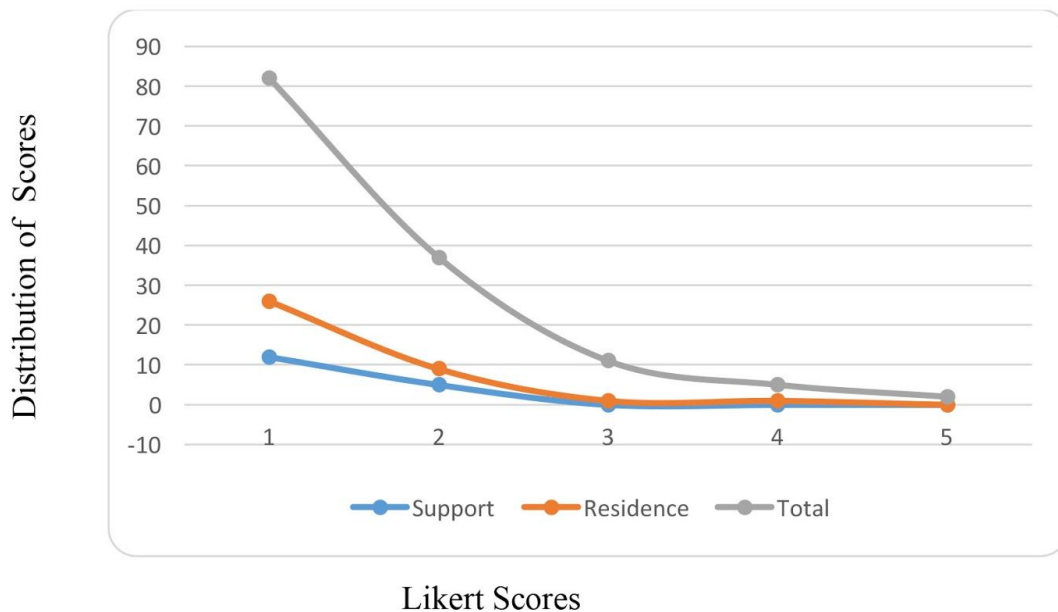
### Comparisons Across the Five Domains

An analysis of the positivity of each of the five separate key issue categories was conducted. These five categories were: Residence (“How happy are you living where you live?”); Support (“How happy/satisfied are you with the help you receive?”); Health (“How is your health?”); Change in Health (“How has your health changed as you’ve gotten older?”) and Life Satisfaction (“How happy/satisfied are you with your life today?”).

For the first domain, Residence, there was a ratio of 0.99 positive to negative statements. This is very close to a completely neutral position, with approximately as many negative comments as positive ones. However, the mean Likert-type scale score for this domain was very high at 1.45, with 14 of the 20 participants rating their happiness as “very happy”. Overall, this

result seems to be contradictory as a Likert mean score closer to 3 (neutral) would have been more expected.

The second domain related to the Support received by each individual. The ratio of 2.62 positive to negative statements indicated that the study participants were generally very happy with the support provided to them. However, the overall Likert-type scale average for this question was very similar to the first domain (1.4). The Likert result is closer to what the interviews would predict, with a high ratio of positive statements corresponding to a high Likert score for this domain. The distribution pattern of Likert scores for Residence and Support were both similar to the overall distribution, as shown in Figure 3 below.

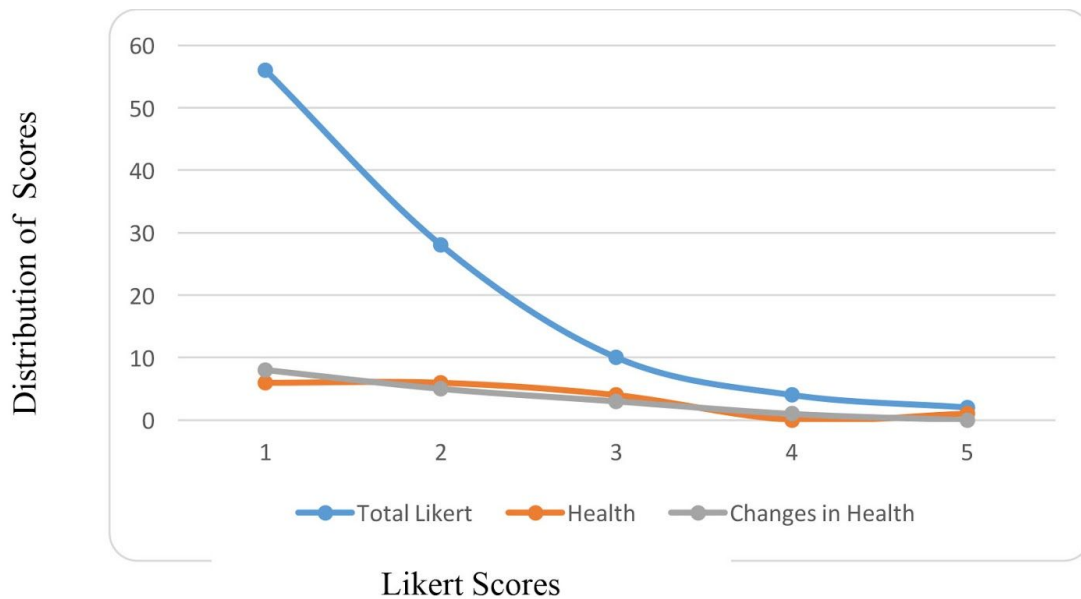


**Figure 3 Total Likert Scores Versus Likert Scores for Support and Residence**

Alternative text description – The image depicts a three line chart of the distribution of scores from 0-90 on the y-axis in relations to a five point Likert scores on the x-axis with the three lines measuring the support, residence and total as described in the previous paragraph. The line chart for supports likert score 1 has a distribution score of ~12, likert score 2 has a distribution score of ~7, likert score 3 has a distribution score of ~0, likert score 4 has a distribution score of ~0, and likert score 5 has a distribution score of ~0. The line chart for residence likert score 1 has a distribution score of ~27, likert score 2 has a distribution score of ~10, likert score 3 has a distribution score of ~0, likert score 4 has a distribution score of ~0, and likert score 5 has a distribution score of ~0. The line chart for total likert score 1 has a distribution score of ~81,

likert score 2 has a distribution score of ~31, likert score 3 has a distribution score of ~12, likert score 4 has a distribution score of ~8, and likert score 5 has a distribution score of ~2.

The third domain, Health, showed a neutral ratio of 1.1 positive to negative statements. The Likert-type scale mean for this question was 2.2, which is indicative of a generally positive perspective rather than a neutral one. The fourth domain, Changes in Health, revealed a very strong negative bias in the statements, with a ratio of 0.26 positive statements for every negative one. However, the mean Likert score was 1.95, which indicated a comparable, or in fact a slightly more positive position, to that of the Health domain. Figure 4 shows the similarity in the Likert score distribution for the Health and Changes in Health domains.

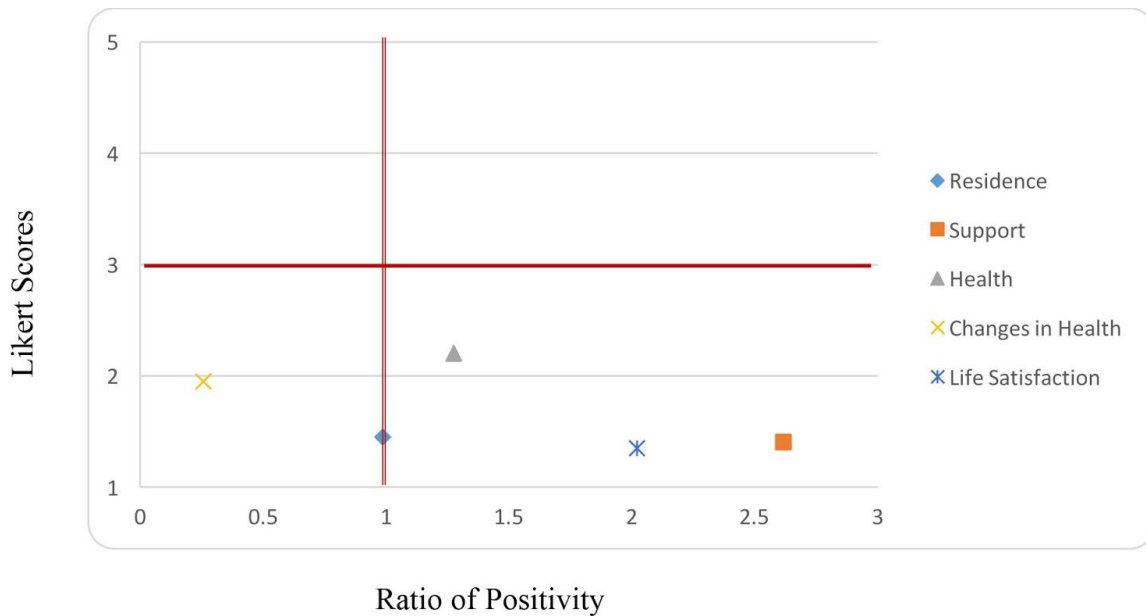


**Figure 4 Total Likert Scores Against Likert Scores for Domains 3 and 4**

Alternative text description – The image depicts a three line chart of the distribution of scores from 0-60 on the y-axis in relations to a five point Likert scores on the x-axis with the three lines measuring the Total Likert, health or changes in health as described in the previous paragraph. The line chart for total likert score 1 has a distribution score of ~58, likert score 2 has a distribution score of ~28, likert score 3 has a distribution score of ~10, likert score 4 has a distribution score of ~4, and likert score 5 has a distribution score of ~2. The line chart for health likert score 1 has a distribution score of ~5, likert score 2 has a distribution score of ~6, likert score 3 has a distribution score of ~4, likert score 4 has a distribution score of ~0, and likert score 5 has a distribution score of ~2. The line chart for changes in health score 1 has a distribution score of ~8, likert score 2 has a distribution score of ~5, likert score 3 has a distribution score of ~4, likert score 4 has a distribution score of ~1, and likert score 5 has a distribution score of ~0.

The final domain, Life Satisfaction, covered a wide range of issues with respect to the interviews. The overall ratio of positive to negative statements was 2.0 which indicated two positive statements for every negative one. The Likert-type scale mean score of 1.35 is again very positive, and the 2:1 ratio would appear to support this Likert score.

Figure 5 shows a scatter plot map of the interview mean positivity scores compared to the relevant domain mean Likert score. Lines indicating neutral positions (3 on the Likert axis and 1 on the positivity axis) have been included. While there visually appears to be a general tendency across all five domains for high Likert scores, this trend is not matched by the positivity scores which are distributed widely and it is difficult to discern any pattern.



**Figure 5 Scatter Plot of Positivity Ratio Versus Likert Score for Each Domain**

Alternative text description – The image depicts a XY chart that compares the ratio of positivity (0, 0.5, 1, 1.5, 2, 2.5 and 3) on the x-axis to a five point Likert score on the y-axis. The measurements were based on residence, support, health, changes in health, and life satisfaction. As stated in the previous paragraph neutral positions were indicated with a solid line on the 3 on the Likert axis and 1 on the positivity axis. The changes in health has a Ratio of Positivity ~0.2 and likert score of ~less than 2; Residence has a Ratio of Positivity ~1 and likert score of ~1.2; Health has a Ratio of Positivity ~1.3 and likert score of ~2.2; Life Satisfaction has a Ratio of Positivity ~2 and likert score of ~1.2; and Support has a Ratio of Positivity ~2.6 and likert score of ~1.3;

While the overall responses to interviews were generally skewed towards a positive score, the ratio of 1.48 positive statements to negative statements does not appear particularly strong.

The responses on the Likert-type scales are far more positive than what would be predicted by the interview data, both overall and specifically in the domains. On the basis of these preliminary analyses, it would appear that there is a discrepancy between what study participants were telling the interviewer verbally, and what they are indicating on the Likert-type scales.

An example of the contradictory nature of the results can be seen when comparing the third domain Health to the fourth domain Changes in Health. There was a very strong negative bias in the statements for Changes in Health, with a ratio of 0.26 positive statements for every negative one. However, the mean Likert score for this domain was 1.95 which represents a similar position to that seen in Health. With the sample being composed of older individuals who are likely to be experiencing increasing health problems associated with aging, the overall negativity of the interview responses in relation to changing health needs was to be expected. However, the strong positivity of the Likert-type scale for the domain does not seem consistent with the views expressed in the interviews.

### Discussion

In the field of intellectual disability, Likert-type scales are often used as an alternative mechanism to seek the opinion of individuals who may not otherwise be able to verbalize their thoughts effectively. In this scenario, there is an implicit but largely untested belief that the two methods will yield equivalent results. The current study used two purpose-developed tools that specifically examined the same key domains. If the Likert-type scores from the current study were presented to a government funding body in isolation, it would appear that adults aging with an intellectual disability are generally very happy with all aspects of their lives and the support they receive. However, when the interview data is also included, the current project indicated little relationship between the Likert-type scale data and the overall positivity of the interviews, with a wide range of scores across the five domains.

The inconsistencies are demonstrated by the fact that the Likert-type scale data indicated that the perceived health of this cohort is actually improving as they get older. Direct comparison of the Likert-type scores versus the matched personal interview shows a number of individuals who quantitatively on the Likert-type scale indicated a perception that their health had improved as they aged, but qualitatively outlined a multitude of health conditions that had both emerged in recent years and had caused significant personal hardship.

It is speculated that there are a number of reasons for the discrepancy between the two measurements. One of the themes anecdotally evident in many of the interviews was an enhanced sense of self-esteem that emerged simply from being asked for their contribution. A number of participants informally commented that this was the first time they had ever been directly interviewed by 'researchers', and where their opinion was both sought and was seen to

be valued. This sense of importance may have contributed to an over-estimation of scores within the Likert-type scales.

Likert tools by their very nature may tend to capture a 'snapshot' of the participant at that particular point in time, whereas interviews are able to explore issues based on a series of statements encapsulating longer-term views. In terms of the health example, the individual may have felt 'good' on the day of the interview as a result of the external focus and attention being specifically paid to them, which led to higher reported scores on the Likert-type scale. However, in the course of the qualitative interview the individual and interviewer were able to discuss and consider other aspects of their health over a period of time. The individuals were able to more clearly articulate their actual health problems, and the summary 'picture' of their health then became far less positive. These findings concur with the work by Owen & Wilson that the abstract concept of 'time' presents difficulties for many people with intellectual disability; and a simple snapshot such as a Likert-type scale can further magnify this problem when considering changes that have occurred over a period of months or years (Owen & Wilson, 2006).

The other important issue that needs to be considered is whether people with intellectual disability are conditioned to pick the 'smiley face' option. The concept of acquiescence bias in verbal interviews is well known (Rapley & Antaki, 1996), and it is entirely possible that participants are showing a similar trend of acquiescence towards picking the smiley face on a Likert-type scale even when it completely contradicts the information they have just verbally offered. The use of pictorial communication systems by individuals with intellectual disability and/or communication impairments has been commonplace both during and post-school for many decades (e.g. Mirenda & Locke, 1989; Stephenson & Linfoot, 1996). In fact, using pictorials such as smiley faces to supplement Likert-type scales has been recommended to overcome acquiescence bias (Heal & Sigelman, 1995). However, it is problematic if the smiley face itself is subject to potential issues of acquiescence. Concerns regarding acquiescence and relying purely on one data source have been previously identified as a serious issue for people with cognitive impairments (Beadle-Brown et al., 2012; Cuskelly, Moni, Lloyd & Jobling, 2013) and the results of the current investigation tend to support this position, however the small size of this pilot means that further research is required to better examine this possibility.

### **Limitations**

This was a pilot study, there are a number of acknowledged limitations, and any results need to be considered with caution. The study only looked at a total of 20 individuals, spread across two states of Australia. While this sample size is not necessarily small for qualitative interview data analysis, it is recognized to be lower than desirable when analyzing Likert-type scales responses. It is possible that the results seen in the current pilot may be diminished if the sample



size was increased; however, the overall consistent positivity of the Likert responses would indicate that it is unlikely to disappear completely.

As noted earlier, it is also acknowledged that the Likert-type scale used did not contain any 'acquiescence' questions to ascertain if questions were being answered illogically. This was deliberate, as many support organization surveys and workplace tools do not use such methodology to check the consistency of participant responses. In any subsequent research, it is recommended to include such questions as it may assist to begin differentiating between various cohort responses within the sample.

### **Implications**

As acknowledged above, this is a pilot study and the findings therefore need to be considered with caution. However, the results of this research have potential implications for services that use Likert-type tools as an approximation of other methodologies, such as personal interview, in seeking contribution from individuals with an intellectual disability. This is a situation that may increasingly arise in Australia with the current movement towards a National Disability Insurance Scheme. As more people receive individualized funding packages and have a greater level of personal control, their direct participation in making decisions about their life should be vital. However, if the person is unable to clearly articulate their thoughts verbally, the question that arises is how to best support the individual to contribute.

The current study provides preliminary data to indicate that Likert-type scales do not necessarily provide an equivalent result to an in-depth interview in a cohort of people able to respond in either format. It is also recognized that responding to an interviewer may have its own set of constraints, including acquiescence to an authority figure, capacity to read facial expressions and non-verbal cues, and so forth. Therefore, it is arguable that solely using any one tool to gain the input of people with intellectual disability or communication impairments is going to accurately represent their thoughts and desires.

A practical example of the dilemma can be seen with voting on an enterprise agreement within an employment environment for people with intellectual disability. Likert-type tools are often used to legally gauge the level of support for a new workplace agreement. For example, Australian Disability Enterprises (ADE) provides workplace support for people with disabilities (Department of Social Services, 2014a). Many of these services have operated under a formal enterprise bargaining agreement and wage assessment system, and voting for these enterprise agreements can include both verbal and written responses. This approach is designed to facilitate the direct involvement of all affected individuals, which in the context of a specialist disability employment support service, can include persons with more severe intellectual disability and communication impairments. Tools that are used to assess understanding and agreement to an enterprise agreement can include simple Likert-type scales and / or short interview. All

participants in the voting process are independently supported to ensure, as best as possible, that they understand the agreement under debate (Department of Social Services, 2014b). The results of the current study raise a question as to whether the responses solely gathered through Likert-type questionnaires can be considered to be equivalent to those individuals who verbally indicated their support, and therefore there could arguably be a legal question regarding the validity of the voting process.

The findings indicate a need to re-consider how participation from individuals with intellectual disability is supported, and how information is gathered. Current legislation and guidelines in Australia refers to the need to optimize communication to facilitate the personal participation of individuals with intellectual disability (e.g. Families & Community Services, 2014), but there are no details on exactly how this is to occur, or whether different approaches can be considered to provide equivalent outcomes. Whilst further research is required to better establish whether there is a significant discrepancy between information gathered via personal interview and other methodologies, the preliminary implications indicate a need to review government legislation to ensure all people have an equal opportunity to have their views accurately represented.

### **Conclusions**

With the recent introduction of wide-ranging changes to the way disability support is provided in Australia, there has been, and will continue to be, a very necessary and desirable attempt to increase the direct contribution of individuals with an intellectual disability in the development of their own programs and life goals. However, there is little research that examines whether differing methodologies of seeking this input produce equivalent outcomes. The current pilot study with 20 older adults with an intellectual disability found a significant difference between what was verbally indicated through interview and what was reported on a Likert-type scale. This discrepancy indicates that there may be problems with using either methodology as equivalent mechanisms for seeking the contribution of individuals with intellectual disability who may have communication impairments. It is acknowledged that this is a pilot study, and it is therefore recommended that further research be conducted with a larger sample size to see if these results are replicated.

### **Acknowledgements**

This research was supported through funding from Illawarra Retirement Trust and the Disability Policy Research Working Group. The authors further acknowledge the contribution made by the Collaborative Research Network on Mental Health and Well-being in Rural Communities, supported by the Department of Industry, Innovation, Science, Research and Tertiary Education, Commonwealth Government of Australia.

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## Research Articles

### **To Include or Not to Include? Realities, Challenges and Resistances to the Participation of People with Disabilities in Seniors' Organizations**

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**Abstract:** People with disabilities are often excluded from mainstream seniors' organizations. A participatory action research project was undertaken in a seniors' leisure association to better include members with disabilities. Results underline the importance of understanding the interaction of individual and environmental factors when looking to support the participation of seniors with disabilities.

**Keywords:** Social participation; Inclusion; Senior

### **Introduction**

Contemporary discourses on demographic aging emphasize the value of older people's social participation as a way to maintain both optimal health (World Health Organization, 2002, 2007) and social roles (United Nations, 2002, 2008). In most countries with an aging population, numerous formal seniors' organizations offer a wide variety of participation opportunities such as volunteering, social and recreational activities. However, although many older people may choose to go to such participatory spaces and find meaningful and satisfactory forms of involvement there (Gilmour, 2012; Zedlewski & Butrica, 2007), those settings may be less accessible to people with disabilities (Lacroix & Raymond, 2015). Various factors could make it difficult for them to join such organizations--architectural and physical issues or ableism-linked attitudes.

Since the absolute number of older people with disabilities will increase as the population ages (Institut de la statistique du Québec, 2013; World Health Organization, 2014), it is urgent to consider how to improve the access of older people with disabilities to, or prevent their exclusion from, mainstream seniors' participatory settings. Though such efforts have been and continue to be made in educational and work environments (United Nations, 2006, 2014), they are much less noticeable in older people's clubs, associations and movements (Bigby & Balandin, 2005; National Council on Ageing and Older People & National Disability Authority, 2006; Russell, 2009). This situation echoes the paucity of evidence addressing this issue in the scientific literature or public policy regarding the realities of aging with disabilities (Jeppsson Grassman & Whitaker, 2013). Reasons for this lack of visibility include, until recently, the relatively limited longevity of people with disabilities (Sheets, 2010; Verbrugge & Yang, 2002) as well as the

desire of disability researchers and activists not to conflate disability with the concepts of decline or illness commonly associated with aging (Jönson & Taghizadeh Larsson, 2009).

Therefore, when the board members of a seniors' leisure association, the Compagnie des jeunes retraités du Plateau de Charlesbourg ("Young Retirees Group," hereafter CJR) asked for our support in developing an internal policy aimed at including people with disabilities in their activities, it seemed like an exceptional opportunity to study the issue empirically, following a three-year participatory research project with older people with disabilities concerning their experiences of social participation (Raymond & Grenier, 2015; Raymond, Grenier, & Hanley, 2014). We assumed that the proposal made to us was the chance to turn the situation upside down and better understand how older people "without disabilities" consider the presence and participation of older people "with disabilities" in "their" organizations. A participatory action research (PAR) project was undertaken around the implementation of CJR's inclusion policy that combined data collection regarding members' needs and visions, raising awareness of various aspects of aging, impairments and activity limitations, and trying different solutions on the individual and collective level. This article presents the results of the first wave of data collection, which explored CJR members' thoughts and experiences with regard to including members with disabilities. The aim was to better understand some of the realities, challenges and resistance related to the implementation of an inclusion policy in the association.

This article begins by highlighting trends in the literature concerning the participation of older people with disabilities in mainstream community settings and the emphasis on personal factors rather than organizational conditions. It then introduces the chosen theoretical model, the Human Development Model - Disability Creation Process, version 2 (HDM-DCP2), which links personal and environmental factors of social participation. This led us to more acute insights about how discourses and practices with respect to inclusion are framed in CJR. Next, the details of the participatory method used in the CJR project is outlined and results are provided concerning how micro, meso and macro factors mediated the possibilities for people with disabilities to be included in the association, shifting the focus from individual factors to more collective ones. Discussions focused on the challenges and tensions that emerged from considering the inclusion of people with disabilities as a social problem needing to be cooperatively addressed rather than as individual accommodations needing to be made each time, or as problematic demands disrupting the normal course of events occurred. It is essential to understand this change of perspective if we want to achieve inclusion for all.

### **Literature Review: A Missing Intersection**

Participation and inclusion have been core themes of international social movements and research in the field of disability for the last four decades (Barnes & Mercer, 2013; Fougeyrollas & Gaucher, 2013; United Nations, 2014). However, the implementation of such ideas has tended to focus on issues that affect children and working age adults such as education, parenting and

employment (Ingvaldsen & Balandin, 2011; Priestley, 2003). Even when it does address the social participation of older people with disabilities, most of the literature focuses on work-like activities such as volunteering (Balandin, Llewellyn, Dew, Ballin, & Schneider, 2006; Narushima, 2005; Tang, 2009). Inclusion in cultural, political or leisure activities has received little attention.

This lack of attention is surprising, considering that studies have linked social participation and health (Baker & al., 2005). Although the benefits of social participation on health are well-known, identifying direct correlation is more difficult (Wahrendorf & al., 2006). However, participation is associated with a more efficient promotion of health and prevention of diseases (Bath & Deeg, 2005; Zuzunegui, 2003), an enhanced adjustment to transition through role substitution (Choi & al., 2007; Van Willigen, 2000), and more frequent and satisfying social contacts (Litwin & Shiovitz-Ezra, 2006; Wahrendorf & al., 2006). Moreover, participation in organized sports, sociocultural or other leisure activities are known to create both a pretext to go out and a shared space where people can meet their individual needs while helping others (Raymond, Sévigny & al. 2015). Seniors who participate in this kind of setting show better health (Cohen & al., 2006), involvement in more activities (Cohen & al., 2006; O'Shea & al., 2012), and more social contacts (O'Shea & al., 2012; Wang & Glicksman, 2013).

However, few studies have focused on the societal participation of older people with disabilities in mainstream community settings (Lacroix & Raymond, 2015). At present, it seems that older people with disabilities are more likely to be included in specialized settings--with organizations that have trained staff and can offer adapted services (Savard, Leduc, Lebel, Beland, & Bergman, 2009; Strain, 2001). However, one study showed that even if going to such centres has a positive outcome, they do not cater to the needs of people who have been included in "normal settings" their whole life (Gaugler & Zarit, 2001). Even though people with disabilities may face numerous obstacles when trying to participate in mainstream associations (Raymond, 2014; Raymond, Grenier, & Hanley, 2014), with appropriate accommodations and assistance they could participate actively in community life (Bickenbach et al., 2012).

The potential to participate in chosen, significant, and self-realizing activities requires contextual and individual conditions for access to be met (Jeppsson Grassman, 2013). Most studies examining the participation of older people with disabilities focused on individual factors, such as cognitive, sensory, and physical limitations (Anaby et al., 2009; Paillard-Borg, Wang, Winblad, & Fratiglioni, 2009). Their impacts on participation are well-documented and guide appropriate interventions by rehabilitation specialists on a personal level. However, this approach puts the responsibility for inclusion solely on the shoulders of the person with disabilities (Balandin, Llewellyn, Dew, & Ballin, 2006; McConkey & Collins, 2010; Percival & Hanson, 2005).

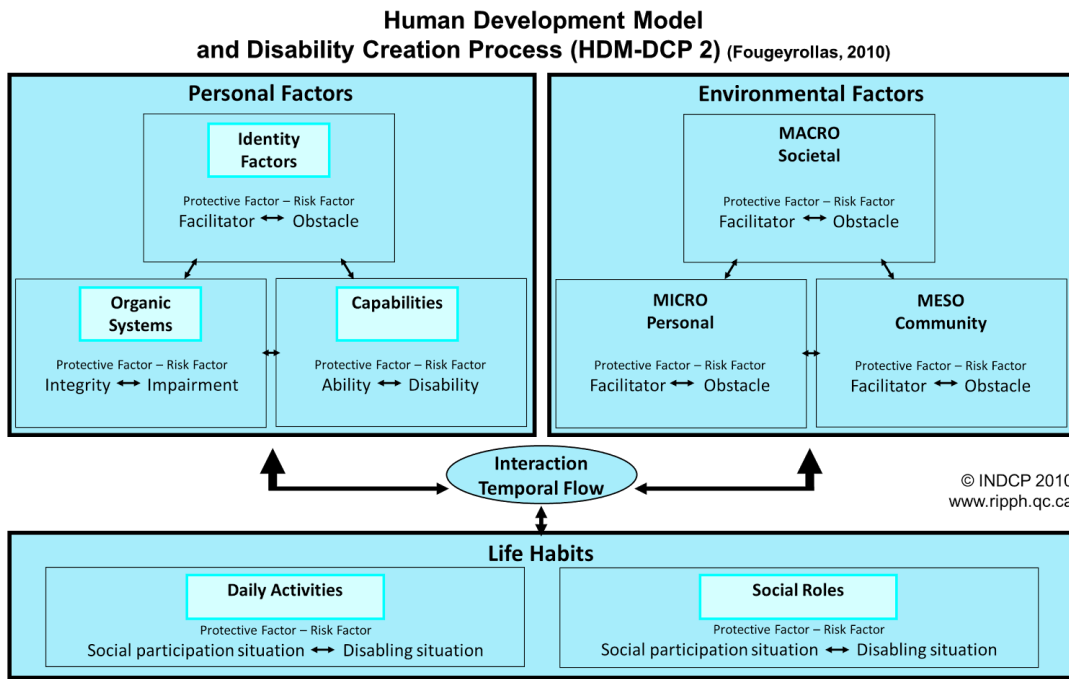
In other words, the literature is inconclusive about how best to support the involvement of older people with disabilities at the community level. However, certain trends point to realities that can limit the participation of older people with disabilities in mainstream organizations, especially in the adaptation of activities and reactions of other participants. For the organization itself, adapting activities to the needs of people with disabilities can be challenging (Tang, Morrow-Howell, & Choi, 2010). For the staff, accommodations are seen as affecting the experience and satisfaction of other participants, thereby limiting service delivery for all (Balandin et al., 2006; Ingvaldsen & Balandin, 2011). This viewpoint shows a lack of knowledge among people working in seniors' organizations (Balandin, Llewellyn, Dew, & Ballin, 2006; McConkey & Collins, 2010). Even though staff understand the importance of including all older people, researchers concluded that it might be difficult to achieve this goal without more specialized workers trained to provide individual assistance to people with disabilities (Balandin, Llewellyn, Dew, & Ballin, 2006; Bigby & Balandin, 2005; Ingvaldsen & Balandin, 2011). In addition, physical obstacles often prevent access to the locations where mainstream organizations conduct their activities (Bigby & Balandin, 2005).

In short, some studies have started to explore problematic issues at the interface between aging and disability, with one such issue being equal access to social activities. However, results are scarce, are often related to a specific reality such as intellectual disability, and do not provide an evaluation of actions that can make changes at the environmental level, ensuring inclusion for all. This study fills this gap by documenting the vision of inclusion articulated by members of CJR.

### **Human Development Model - Disability Creation Process**

The Human Development Model - Disability Creation Process (HDM-DCP2) shown in Figure 1 is a theoretical model that considers disability as a relative reality, constructed through the connection of biological, functional, physical and cultural elements. There are no disabled people per se, but rather people unable to perform their daily activities and social roles because of an inadequate interaction between personal and environmental factors (Fougeyrollas, 2010). Such inadequacies put individuals in a disabling position while an adequate interaction would allow them to achieve social participation. Both personal and environmental factors can act as facilitators or obstacles to social participation. Personal factors include the individual's identity, organic systems and capabilities. Environmental factors refer to dimensions defining the way a society is organized. The model posits three categories of environmental factors: personal (micro), community (meso) and societal (macro) (Fougeyrollas, 2010). The personal environment consists of things in the person's immediate environment, such as family and friends. The community environment comprises organizations and services used by the person outside the home. Finally, the societal environment contains rules, regulations and programs that can affect the individual's participation.

Figure 1: Human Development Model - Disability Creation Process (HDM-DCP2)



Summary of Figure 1 entitled Human Development Model – Disability Creation Process (HDM-DCP2). This image is composed of two squares and one rectangle. The top left square illustrates personal factors. Inside this square, three components of personal factors are detailed: first, identity factors, which can be placed on a continuum, symbolized by a bidirectional arrow, between facilitator and obstacle; second, organic systems, between integrity and impairment; and third, capabilities, between ability and disability. The top right square illustrates environmental factors. Inside this square, three components of environmental factors are detailed: macro societal, micro personal and meso community factors. These three factors can be placed on a continuum, symbolized by a bidirectional arrow, between facilitator and obstacle. Below those squares is a rectangle illustrating all of the life habits: daily activities on the left and social roles on the right. Both are placed on a continuum, symbolized by a bidirectional arrow, between social participation situations and disabling situations. Between these shapes is an oval conveying the reciprocal relationships and temporal flow between all components by means of bidirectional arrows. The possibility for a person to realize her life habits his linked to the interaction and flow between personal and environmental factors.

The HDM-DCP2 model helps to understand and potentially modify disabling settings and dynamics. Since it conveys the whole experience of disability, like other relational models (Shakespeare, 2014), it does not focus primarily on medical or structural factors. In our case, the HDM-DCP2 model enabled us to tackle complexity when analyzing how discourses and practices with respect to the inclusion of members with impairments are framed in CJR. For

instance, the emphasis on individual biological or attitudinal factors to explain the social participation of older people with disabilities, so dominant in both scientific and population discourses, could be revisited and connected to collective, contextual factors, but without overlooking the importance of personal realities.

### Participatory Methods

The results presented here are derived from a participatory action research project rooted in CJR, a seniors' leisure association offering its 1800 members more than 100 activities each year. As a non-profit organization, it is managed by a group of 120 volunteers, board members and activity managers. It offers a wide variety of activities, such as sports (tennis, walking group, snowshoeing, cycling, cross-country skiing, golf, etc.), social (meetings, conferences, dance classes, etc.), cultural (museum visits, signing group, language classes, music shows, etc.), travel, etc. The association was created in the mid-1990s, a period marked by the objective of attaining "zero deficits", or provincial budget balance. Numerous public employees obtained an early retirement, hence the name "Young retirees" in CJR's name. So in 1994, a group of recently retired individuals from a White and middle-class neighbourhood decided to create a social club allowing for more "active" or "dynamic" leisure compared to typical golden-age activities.

When celebrating CJR's 20<sup>th</sup> anniversary in 2014, the board members realized that their aging membership (50% of members were 70 and older) was starting to face limitations in their participation. To avoid having anyone leave the organization because of disabilities, in 2013 they adopted an internal policy on inclusion. This document laid the groundwork for the definition of key concepts, such as inclusion, disabilities, and social participation. It also promotes the values important for the association. However, the application of the policy was not operationalized. A Participatory Action Research (PAR) project was set up to ensure proper implementation and evaluation of this policy. A three-year research grant for the project was obtained from the government of Québec, one of ten provincial administrations in Canada.

While PAR encompasses a wide variety of research practices, it is fundamentally about involving people in the production of knowledge regarding problems that concern them, and in the framing and application of solutions that are in line with their experience (Chevalier & Buckles, 2008; Reason & Bradbury, 2008). It appeared to be a meaningful approach for CJR members, who were eager to be at the forefront of the project. Undertaking PAR involves trying to change the relationships between researchers and participants in both the process and the outcomes of the research; the sharing of expertise, power and responsibility is experienced as a tool to build mutual benefits, create relevant data and achieve social change (Bradbury & Reason, 2003; Fals Borda, 2001; Pain, Kindon, & Kesby, 2007; Reason & Bradbury, 2001). From the outset of the PAR project, we created a "research group" composed of seven CJR members, a social worker, an academic (1<sup>st</sup> author) and a research assistant (2<sup>nd</sup> author). Members participated in all research steps and tasks: developing the research protocol, designing

the data collection tools, leading or co-leading the interviews, analyzing and interpreting the data. The researcher and research assistant provided training for the committee members to ensure that all participants were informed and comfortable.

The first phase of the project consisted of collecting data about what CJR members thought and experienced with regard to the inclusion of members with disabilities. Our aim was to better understand the circumstances, dilemmas, possibilities and conflicts related to the implementation of an inclusion policy in the association. Two methods were used. First, individual interviews were conducted with members who manage the association's activities. Second, seven focus groups were conducted with members. In all, 60 participants were invited to share their perceptions in response to questions. We saw these individual and group interviews not only as a way to gather useful data for the implementation of the policy but also to sow the seeds of change within CJR, making people aware of the research project and its goals. The questions guiding the interviews could be summarized as follows: in CJR, could members who develop impairments remain involved in chosen activities? Could prospective new members with different types of disabilities be admitted and included? Following the dissemination and acceptance of the results in CJR, we planned to develop solutions to the problems identified.

All interviews and focus groups were recorded and transcribed, and N'Vivo was used to categorize text segments from the transcripts into open categories at first (individual factors, environmental factors, solutions, exclusion situation), followed by more selective coding designed to make principal obstacles emerge (Creswell, 2013). Validity of the results was supported by three strategies, some of which involved the participants themselves (Padgett, 2008): prolonged engagement in the field for the research team involved; member checking by participants of the project in all steps; and peer debriefing and support. Reliability was ensured by using intercoder agreement in all the coding steps, including development of the codebook and the actual coding (Creswell, 2013). Each source was coded independently by a member of the research team and a CJR member. Agreement reached 70%, which was considered acceptable since it was the first experience with research for many of the members.

## Results

The results presented here show the perspective of CJR members reflecting on the rationale of including fellow members who already have or develop disabilities, and the inherent challenges and difficulties involved in doing so. They offer unique insights concerning a central question in aging societies: Would an increasing number of older people with disabilities be able to join mainstream participatory spaces, including seniors' organizations? It is essential to answer this question if we are to achieve equity in both aging policies and trajectories.

In total, we collected information from seven focus groups (46 participants) and twelve individual interviews (14 participants; three asked to do the interview together since they managed the same activity). Composition of the sample is shown in Table 1.

**Table 1: Distribution of sample by source, age and sex (W=Women, M=men)**

Source	Age/Sex	Source	Age/Sex	Source	Mean age/Sex
Interview 1	76/M	Interview 7-8-9	70/1W-2M	Group 1	70/6W
Interview 2	67/M	Interview 10	66/M	Group 2	75/2W-2M
Interview 3	*/W	Interview 11	70/W	Group 3	71/7W-1M
Interview 4	72/M	Interview 12	66/M	Group 4	75/3W-3M
Interview 5	67/M	Interview 13	71/W	Group 5	74/5W-7M
Interview 6	76/M	Interview 14	70/W	Group 6	70/5W-1M
				Group 7	70/2W-2M

\* Participant refused to give her age

Factors influencing social participation can be categorized, as suggested by the HDM-DCP2, into individual and environmental dimensions. Since our aim is to gain a better understanding of how CJR members feel about the implementation of an inclusion policy in their organization, results focus on environmental factors that are seen to support or hamper inclusion, i.e., micro (how “regular” CJR members talk and act about disabilities), meso (how activities are planned and carried out in CJR) and macro (the discourses and management structuring CJR) environmental factors. The results section ends by addressing how individual factors in the group targeted by the inclusion policy, i.e., members with disabilities, are framed in the participants’ accounts.

**Micro Environment: Them vs. Us**

This first category of environmental factors led us to consider how CJR members’ ideas and interactions concerning inclusion might impact the inclusion policy. From the start, it must be said that the way disability was conceived by the study participants was profoundly anchored in the metaphor of fatality, which also ties in with the way aging is constructed. Following that logic, participation seems unattainable after a certain age. Here, being too old appears to be a convincing reason to abandon an activity:

“At one point, you have to limit your activities, it’s unreasonable [to continue], you’ve reached that point, you are 72 years old.” (Interview 12)

While aging is mentioned as a negative discourse, as something people don’t want to think about, a loss of capacities is seen as its worst outcome:



“[People will say]: my good days are gone. [...] We can’t escape it [aging]. It’s an eye-opener, people are scared.” (Group 5)

“I think that when you get older, you have to grieve for all of your abilities that decline progressively.” (Interview 5)

Even though aging and disability are linked in people’s minds, the latter being the unavoidable result of the former, the study participants distinguished between “active”, “normal” older people, who made up the majority of CJR members, and older people with disabilities. When speaking about the participation challenges faced by people with disabilities, it was mostly a matter of “them,” not “us”:

“These people [with disabilities] are always exceptional cases. (...) As a rule, you organize your activity for normal situations.” (Interview 1)

Since acquiring or developing disabilities is constructed as a predictable but (hopefully postponed) dark side of aging, when it happens it might entail a mix of giving up and coping. For instance, members in this situation should accept their situation, be nice, reframe the nature of their involvement and ask for help when necessary:

“I noticed that high achievers especially, when they experience difficulties, find it hard to accept a change of group [level], even if it would be more enjoyable. It’s a difficult situation to accept.” (Interview 5)

“That’s how it is. You have to accept that you have a problem: it is not CJR’s problem. Adapt, make changes if you can; if you can’t do it [the activity] anymore, just stop and do something else.” (Group 4)

However, when the individuals concerned were well-integrated in the CJR before the onset of disabilities, when they were supported by a group of close relatives, the impact of impairment seemed to be attenuated:\

“So he came, his wife picks up the balls for him and gives them to him directly in his hand so he can shoot. The other members were OK with this, we’ve known him for several years, and everything was fine. He was a lot slower than he used to be, but everyone accepted him. He kept his cheerful attitude and all was good.” (Interview 3)

“Speaking of him [man with a disability], we found a way to give him the impression of still being part of the activity, he drives the back-up car [during a biking expedition]. We always need one or two of those. He is happy; he follows his group of friends with whom

he spent time for years, while still being useful if someone has a problem or an accident.” (Interview 4)

Thus, in some ways, micro discourses about the CJR inclusion policy restricted the goal of being more welcoming to people with disabilities to a specific aspect that makes it the exception, not the norm:

### **Meso Environment: Accommodation Up to a Certain Point**

In the context of a leisure association offering hundreds of activities for older people, implementation of an inclusion policy is likely to be profoundly mediated by the way things are managed at the organizational and interactional levels.

Volunteers are responsible for planning and running activities and this seems to be a huge responsibility:

“It [planning the activity] will become burdensome, I agreed to get involved but it can be... I don’t want to have more work than when I was working.” (Interview 5)

Including people with disabilities in their activities poses an additional challenge for organizers. Some leaders lack knowledge of the realities and needs of people living with disabilities. Some are not interested in learning the skills necessary to cope with these situations:

“Unfortunately, I do not think that all of the organizers are available or want to spend time and energy preparing to deal with such situations.” (Interview 4)

Including people with disabilities frequently requires some accommodation with respect to architecture, equipment or rhythm. Ineffective accommodation practices can lead to the marginalization or exclusion of the individuals concerned:

“We had to put the balls directly in her hand, almost shoot them for her, pick them up after, she was slowing the whole group. The day after, I called her and told her: “Look, don’t you think that a certain level of flexibility and ease is necessary to play this sport?” [...] She said: “I’d better stop going.” I replied: “I won’t put words in your mouth but that is what I was expecting you to say.” [...] Obviously she never came back. I’ve never seen her again.” (Interview 3)

“I see another problem in that. Twice I’ve seen people stop an activity that they could have continued because of, for example, a foot or knee operation. This situation happened in one group, the person stayed home, she couldn’t come because she couldn’t drive, so she stopped the activity.” (Group 3)

Beyond organizational accommodations, the participants' accounts showed more relational, interactional meso issues. For example, participants expressed a desire for belonging and continuity in the composition of groups. Newcomers or people with disabilities are seen as not being one of the "gang," and thus as jeopardizing the cohesion of the association:

"There are the younger members, barely 60 years old, newcomers to CJR, dynamic and wanting to perform, facing others, 80 years old, slowing the pace of the activity. These people are not always ready to accept constraints; they are here to have fun for themselves." (Interview 4)

When the group decides that someone does not fit in or have his/her place, it is assumed that it is that person's responsibility to realize it and change activities. These situations cause exclusion:

"People will say: she knows she can't do it anymore, she just has to stop coming. This idea will be spread around a lot." (Interview 11)

People in our sample explained this kind of behaviour as being mainly due to a lack of knowledge about disability and a fear of change. It is easier to ignore a problem than address it:

"But I see... there are people who won't accept it. There are some people who can't accept my decreased abilities because I'm not the same person anymore. I won't lie to myself." (Interview 11)

"People don't know what to do. They stand there gaping, they know about the situation but they also know that if they don't talk about it, it may be nipped in the bud, go away... they don't know what to do." (Group 3)

All told, the policy for inclusion was perceived as being superimposed on other policies, emerging from customary ways of doing things and networking.

### **Macro Environment: Shifting Purpose**

Demographic aging and related public policy changes could impact on how disability is handled in a seniors' organization. There is a growing absolute number of older people, which may partly explain why CJR is facing rapid expansion in its membership, from 500 to 1800 in less than a decade. In becoming such a large organization, the study participants wondered if meeting individual needs was realistic:

"Isn't that the problem? When an organization becomes too large, too big, it can't cater to the individual needs of its members." (Group 1)

Secondly, because CJR is managed solely by volunteers, expectations regarding the involvement of organizers in achieving inclusion are seen as necessarily limited:

“As you say, organizers have to be equipped, trained because they don’t know what to do. [...] You see, they are all volunteers and might not know everything. They put together a group, everybody has fun but they don’t always know that there are conflicts in the group.” (Group 3)

“If I put myself in the organizers’ shoes, they have a lot of goodwill but they are all volunteers. They might want to organize an activity but maybe they don’t have the right attitude, aren’t diplomatic enough to know how to tell them [people with disabilities] that [they can’t be in the group anymore].” (Group 7)

Aging of the membership and the ongoing larger proportion of people with disabilities within it raises issues about what the association’s purpose should be. There appears to be a disconnect between sticking to self-governing and stimulating recreational activities and the possibility of adapting or changing CJR to accommodate what are viewed as minority situations:

“It is not the CJR’s responsibility to guide the person toward something else [other activities]. I don’t really know what the CJR could do in such situations [when people with disabilities ask for support].” (Interview 7-8-9)

“It means that we will accommodate them as long as it doesn’t disturb the other participants. Accommodations are individual; if we have to get a little bench for him, we’ll do it, but nothing more. We can’t play for him after all!” (Interview 3)

At the macro level, the policy of inclusion is partly perceived as being overly demanding for CJR, which was founded as a social club for “young” retired people. Again, seeking to integrate disability as something usual that must be taken into account, was felt by the participants to be incompatible with dominant and dichotomizing discourses about the two successive trajectories within aging: before and after the onset of a loss of capabilities.

### **Connecting Environment to Individual Factors: Potential Ignored**

This study did not specifically investigate how CJR members with disabilities envision their own participation and inclusion in the organization. At this stage, we were interested in seeing how “average” members describe individual issues and realities of members with disabilities. Although several participants disclosed disabilities during the interviews and focus groups, they

generally considered their own situation to be different from that of people with “more” or “worse” disabilities.

When invited to describe the characteristics of fellow members with disabilities, the participants overwhelmingly pointed to poor health; in all the interviews and focus groups, it was mentioned as a negative input for inclusion. Whether permanent (loss of mobility, hearing, vision, cognitive problems, depression and anxiety, pain, allergies) or temporary (caused by accident, surgery or disease), health issues are always linked to a decrease in participation. Cognitive limitations especially are seen as making inclusion in a group setting intolerable. Moreover, the large majority of participants mentioned the decline in capacities as restricting participation. While physical limitations (vision, hearing, mobility, and loss of endurance, strength and velocity) are seen as important, two situations can be singled out as particularly incapacitating: loss of the ability to drive and dependence on others to accomplish daily tasks. In sum, people with disabilities are viewed in a negative light that only considers their deficits and ignores their potential or strengths. The linking with environmental factors shows consistency in the dynamics and decisions that have produces exclusion.

### Discussion

Our results confirm the importance of exploring the interaction of individual and environmental factors when seeking to better support the membership and participation of people with disabilities in a seniors’ leisure association. In fact, while the scientific literature still focuses on individual factors when addressing specific needs and difficulties of seniors with disabilities (Lacroix & Raymond, 2015), this study shows that environmental factors are crucial if we do not want disabilities to be the dividing line between older people who can and cannot participate in mainstream community settings.

When analyzing and merging micro, meso and macro environmental factors regarding the inclusion of people with disabilities in CJR, two transversal trends emerged: first, disabilities are seen an exception; second, when members are keen to make some type of accommodation to facilitate the participation of people with disabilities, the regular course of activities must not to be affected. Connected with individual factors, these interpretations point to the participation of members with disabilities in seniors’ organizations as unusual, disconcerting and possibly disruptive. Such tension between personal situations and environmental conditions poses a serious threat to the participatory ideal framing contemporary discourses and policies in both the aging (United Nations, 2008) and disability fields (United Nations, 2014).

Regarding disabilities as being shaped as a somehow singular experience, this result could appear striking since it is known that both the proportion and the absolute number of older people with disabilities are increasing (Murray et al., 2014). For instance, 26% of people aged 65 and over in Québec present moderate or severe disabilities, and this proportion rises to 57% for

all kinds of disabilities (Institut de la statistique du Québec, 2013). But if the intersection of old age and disabilities is far from being the exception, why is it seen this way? Why did our study participants make such a clear distinction between “us” (members without disabilities) and “them” (people with disabilities)?

Many years ago, authors started to address stereotypes associated with older people with disabilities and the fact that older people “without disabilities” do not like to mix with the former, partly because seeing them could evoke the inevitability of future decline, the genuine embodiment of failure (Cohen, 1988; Katz, 1996; Lund & Engelsrud, 2008; Minkler & Fadem, 2002; Pardasani, 2010; Raymond, Grenier, & Hanley, 2014b; Zarb, 1993; Zarb & Oliver, 1993). This dichotomization echoes another dichotomy evident in policy and media discourses, where older people are either healthy and willing to participate in society, or not healthy and expected to stay at home or in specialized settings (Biggs, 2004; Jeppsson Grassman & Whitaker, 2013; Lagacé, Laplante, & Davignon, 2011; Raymond & Grenier, 2013; Rozanova, 2010). Aging successfully is about not looking old, sick or limited (Paillard-Borg et al., 2009; Priestley & Rabiee, 2002).

In CJR’s day-to-day operations, the perception of disability-related realities as something occasional and discontinuous leads to case-by-case management that has the potential for inequity. One problem is anchored in the Victorian rhetoric of deserving and undeserving poor (Katz, 1989), which was also used to critically review disability policy (Roulstone & Prideaux, 2012), i.e., some members with disabilities deserve consideration and accommodation while others do not. If the former are nice, easy-going people, well-known within CJR, eager to admit their limitations and not be too demanding, and willing to accept unsatisfactory but continuing membership, inclusion is likely to be more straightforward and effective. While perceptible at the micro level in the participants’ accounts about fellow members with disabilities, this pervasive posture permeates meso and macro level conditions for participation. In other words, members with disabilities must undertake by themselves the journey of adjusting their involvement in CJR, taking environmental circumstances and factors into account.

Coming back to the second transversal trend in the results, while no one is opposed to virtue and the idea of inclusion looks like an attractive, conceivable solution allowing members with disabilities to participate in CJR, it must not affect the experiences of “regular members” in the association. Indeed, changes likely to improve inclusion are perceived as complicated and annoying. Since it seems unproductive to attribute this (mis)understanding to egotism or apathy, the existing literature could help to understand this reluctance to make changes.

For example, research has documented the difficulty mainstream organizations have when tailoring their activities to the situations and aspirations of people with disabilities, especially group activities (Savard et al., 2009; Tang et al., 2010). In some cases, specific accommodations

are seen as affecting services and collective experiences for people without disabilities, leading organizations to question the way they achieve their mission (Balandin, Llewellyn, Dew, Ballin, & Schneider, 2006; Ingvaldsen & Balandin, 2011). Researchers also found a lack of knowledge regarding the realities of people with disabilities, insufficient resources to provide support when needed, and the inadequacy and inaccessibility of physical settings (Balandin, Llewellyn, Dew, & Ballin, 2006; Bigby & Balandin, 2005; McConkey & Collins, 2010).

It is remarkable to note that these meso obstacles could be preceded or amplified by micro prejudices against older people with disabilities rooted in “local” internal relationships and interactions, or macrosocial narratives about aging and disability (Ingvaldsen & Balandin, 2011; Lund & Engelsrud, 2008; McConkey & Collins, 2010; Paillard-Borg et al., 2009; Priestley & Rabiee, 2002). Moreover, this environmental analysis shows substantial consistency in how people with disabilities are presented in the data. The relational framework proposed by the HDM-DCP2 model helped to identify and explore complexity, showing that the question of inclusion is challenging at all levels.

### **Final Thoughts: How to Produce Change?**

If we accept that older people with disabilities are able (Jeppsson Grassman, 2013) and have the right (United Nations, 2006) to participate in mainstream society, our results demonstrate that it is crucial to view the inclusion of people with disabilities as a collective issue needing to be addressed cooperatively. If we do not want disability to be seen as the disturbing and demanding reality of a minority of older people but as something both normal in an aging trajectory and specific to certain people, if we wish to achieve participation not just for highly functional or elite seniors but for all older people regardless of their state of health, there is work to be done.

In CJR, the next step will be the implementation of practical guidelines for all activities, to help create a more inclusive environment. Following the analysis of these results, the members of the research project decided to focus on four issues: clarifying the mission and policies of the organization to ensure consistency between theory and practice; raising awareness of disability and its impacts in individual and collective terms; offering improved coaching to activity managers to help them plan and achieve their activity; and develop tools to guarantee that all members will feel welcomed in all activities. In the Fall 2016, intervention programs tackling those issues will be tested in five activities and evaluated thanks to a case study methodology. The conclusions will lead to the elaboration of the practical guidelines, supporting a proper implementation of the policy, respectful of the organization’s realities and people.

Of course, older people with disabilities must be at the heart of this agenda for change, not as a special group but as equal older citizens looking for meaningful involvement or activities. Undoubtedly, this implies deconstructing dominant models of aging – or anti-aging - focusing on

health and achievement, and seeking to contribute to what we could call the politics of solidarity in old age.

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## Research Articles

### Compulsory Youthfulness: Intersections of Ableism and Ageism in “Successful Aging” Discourses

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**Abstract:** This article forwards the theory of compulsory youthfulness as a way to explore how ableism, ageism, and other systems of oppression intersect to produce the societal mandate that people must remain youthful and non-disabled throughout the life course, particularly in a cultural context that holds successful aging as an ideal.

**Keywords:** ageism, ableism, intersectionality

Cultural stereotypes of old age as a time of loss, dependence, frailty, and disability prevail. As a result, impairment and illness are largely perceived as the "norms" of late adulthood (Priestley, 2003). Kelley-Moore (2010) referred to this phenomenon as the social construction of causality, and observed, “Becoming disabled prior to old age is framed as non-normative and disruptive to the life course...Alternatively, becoming functionally limited in older adulthood is framed as normative” (p. 107). Thus, disability and old age are inextricably linked, and consequently, so are able-bodiedness/able-mindedness and youthfulness.

In order to counter these stereotypes, the gerontological persuasion, or the “biomedical and social scientists, policy makers, activists, and entrepreneurs interested in the ‘gray market’” (Ballenger, 2006, p. 56), has engaged in ongoing efforts since the 1950s to reframe old age as a time of activity, leisure, able-bodiedness, and health. At the center of these efforts is the concept of successful aging, which emphasizes health and functionality, absence of disease and

disability, and active engagement (Rowe & Kahn, 1998). The successful aging movement exemplifies these increasingly prominent discourses on aging. For example, in 2012, the World Health Organization (WHO) announced that the theme of their annual World Health Day was “Aging and Health.” As part of the campaign, a global news brief, a series of posters, and a video were released, all of which were centered on the slogan “good health adds life to years.” Each form of media featured diverse images of old people from around the world, in which older adults are engaged in activities such as working in various contexts (e.g., at a computer, as a doctor, as a farmer), exercising, caring for children, dancing, and even bungee jumping. In nearly every photo, the old people portrayed appear active, energetic, and able-bodied. Furthermore, the images imply that these old people are taking charge of their health and thus individually responsible for their youthful and non-disabled status.

While aspects of the successful aging movement are engaging in important efforts to dispel negative stereotypes about old age, an intersectional analysis of successful aging demonstrates that an unintended consequence is the creation and promotion of a societal mandate for people to remain youthful and able-bodied throughout the life course, including in old age. Building on the concepts of compulsory heterosexuality (Rich, 1980) and compulsory able-bodiedness (McRuer, 2006), I term this form of oppression supported by the successful aging paradigm compulsory youthfulness. Framed through an intersectional perspective, compulsory youthfulness is produced through ableism and ageism, which are systems of beliefs, values, and practices that create and reinforce youthfulness and able-bodiedness/able-mindedness as ideals, thereby casting old age and disability as devalued states of being (Butler, 1989; Campbell, 2009; Palmore, 1999). Compulsory youthfulness highlights the ways in which ableism and ageism intersect within successful aging discourses to falsely present both being old and being disabled as choices, rather than the result of biological changes and cultural, political, economic, and social structures. As a result, old disabled people are labeled as failures for aging “unsuccessfully” and perceived as responsible for their own vulnerability (Portacolone, 2013; Rubinstein & de Medeiros, 2015).

I forward the neologism of compulsory youthfulness as a way to explore intersections of age and disability in a culture that holds successful aging as an ideal. I introduce this theory as a lens through which to analyze systems of power that survey, police, and discipline young, middle-aged, and old bodies by enforcing the maintenance of youthfulness and able-bodiedness/able-mindedness throughout the life course. First, I define successful aging, discuss its prominence in the field of gerontology, and explore existing criticisms of the concept. I also consider how a lack of collaboration between gerontology and disability studies and their feminist sub-fields, feminist gerontology and feminist disability studies, has limited the opportunities for intersectional critiques of successful aging. Then, I call for the use of intersectionality, as an analytical framework, to further bridge gerontology and disability studies and (re)consider old age and disability collectively, particularly in regards to successful aging

discourses. Lastly, I engage in intersectional analyses of academic texts to explore how compulsory youthfulness enforces ideals of successful aging and thereby mediates the lived experience of old/disabled people in a sociocultural context of ableism and ageism.

### **Successful Aging**

In the 1950s and 1960s, scholars in the emerging discipline of gerontology desired to challenge dominant narratives of old age as a time of loss, illness, and decline (Ballenger, 2006). Early iterations of successful aging consequently emerged (Havighurst, 1961). As Katz and Calasanti (2015) noted, “Successful agers were satisfied, active, independent, self-sufficient, and above all, defiant of traditional narratives of decline” (p. 27, emphasis added). This positive characterization of old age flourished, and in the 1990s, Rowe and Kahn provided a more precise definition of successful aging. Specifically, Rowe and Kahn (1998) asserted that gerontology should focus less on dichotomies of normal and abnormal aging, and more on older adults “aging well.” Successful aging thus became an idealized form of aging. Rowe and Kahn (1998) defined successful aging through three primary components that are independent of each other but hierarchal. To age successfully, one must maintain: (a) “low risk of disease and disease-related disability;” (b) “high mental and physical function;” and (c) “active engagement in life” (p. 38). Since then, successful aging has proliferated. According to Katz and Calasanti (2015), successful aging “has been churned into theoretical paradigms, health measurements, retirement lifestyles, policy agendas, and anti-aging ideals” disseminated through “(a) an industry of books, conferences, journals, funding, and research programs, (b) web sites...and (c) institutional identities” (pp. 26-27). Thus, successful aging has become one of the most dominant gerontological concepts.

### **Critiques of Successful Aging**

Despite its popularity, numerous gerontologists and aging studies scholars have critiqued successful aging. Martinson and Berridge (2015) conducted a systematic review of 67 gerontological articles challenging the idea of successful aging and found four primary types of critiques. The first type, “Add and Stir,” generally found the model of successful aging acceptable, but advocated for successful aging to either adjust the criteria to be less strict (in order for more older adults to meet the criteria), or add criteria to adjust gaps in the current paradigm related to psychological or social dimensions such as adaptation, well-being, and life satisfaction. The second type of critique, “Missing Voices,” called for successful aging models to include diverse older adults’ subjective definitions and perceptions of successful aging. The third category was “Hard Hitting Critiques,” and these critiques had five primary concerns about successful aging: “Its individualistic approach, implied ageism and ableism, neoliberal contexts, negative influences on society and the lived experiences of older adults, and impacts on social justice” (p. 62). These critiques expressed one or more of the aforementioned concerns, and consequently rejected the successful aging paradigm and called for alternative frameworks. The



fourth category was “New Frames and Names.” Similar to the Hard Hitting Critiques, critics in this category rejected successful aging as a paradigm, and also posited alternative frameworks as solutions to the various problems that successful aging presents. Many of these new paradigms retained a focus on the individual, but employed more holistic and integrative approaches.

### **Lack of Intersectional Analyses of Age and Disability in the Successful Aging Paradigm**

The existing critiques of successful aging are important challenges to this dominant paradigm of aging. However, few of these critiques consider multiple and interlocking forms of oppression, demonstrating that more intersectional analyses of successful aging are needed. For instance, of the many critiques, only a select few consider how the ideal of successful aging may be ageist and ableist (e.g., Holstein & Minkler, 2003; Minkler, 1990; Morell, 2003; Stone, 2003). Interestingly, ableism was a term selected by Martinson and Berridge (2015) to describe these critiques. With the exception of Minkler (1990), who used the term handicapism, none of the articles in the review referenced ableism or described it as a system of oppression. Thus, since many of the critiques from gerontologists do not consider disability or ableism, it is essential for disability studies to consider successful aging. Notably, of the 67 articles Martinson and Berridge (2015) included in their systematic review, only one incorporated feminist disability studies perspectives (Morell, 2003).

Furthermore, some scholars recognize that the concept of successful aging harms disabled elders, but term this phenomenon “the new ageism” (Angus & Reeve, 2006, p. 143). This idea is similar to Cohen’s (1988) concept of the “elderly mystique,” which characterized by the ways “American ageism is focused upon the elderly with disabilities, as opposed to well elderly” (p. 25). The issue with these approaches to the oppression of disabled elders is they threaten to redefine ageism as ableism. Doing so inhibits critique of the ways non-disabled elders experience ageism. As Stone (2003) noted, people have many fears about aging, and disability is only one aspect of aversion to aging and older adults. Furthermore, to redefine ageism as ableism prevents scholars from exploring how ageism and ableism intersect, for disabled elders and for people as they progress throughout their life courses.

One of the reasons for a dearth of scholarship on how ageism and ableism interconnect is the lack of integration between disability studies and gerontology (Berger, 2013; Lightfoot, 2007). Furthermore, the feminist sub-fields of these disciplines, feminist gerontology and feminist disability studies, have also remained disparate. In many ways, feminist disability studies and feminist gerontology are fields on parallel paths. Individually, feminist disability studies and feminist gerontology have criticized feminist theory for failing to consider disability (i.e., Garland-Thomson, 2002) and old age (i.e., Calasanti & Slevin, 2006) as identities and analytical tools. Thus, these scholars have engaged in comparable, but disjointed, efforts to encourage the inclusion of disability and age in feminist work. Simultaneously, these scholars

have individually called for their respective disciplines to incorporate feminist theory. Despite these analogous paths, these fields rarely intersect

However, collectively considering aging and disability is imperative; as Verbrugge and Yang (2002) noted, “Disability and aging are processes that interweave throughout the life course” (p. 253). The lack of integration between feminist disability studies and feminist gerontology prevents scholars from understanding and addressing the material, emotional, and social consequences of intersectional oppressions related to disability and old age. Thus, feminist disability studies and feminist gerontology must collaborate to engage in more intersectional analyses of disability and old age.

### **Intersectionality as an Analytical Framework**

Intersectionality offers a way to consider how disability and age intertwine in later life and throughout the life course. Intersectionality, which originated in the work of Black feminists and queer women of color, is a framework for understanding intersecting identities and forms of oppression (Combahee River Collective, 1977; Crenshaw, 1991; Lorde, 1984). Intersectionality challenges the idea that an individual’s lived experience is grounded in a single social identity and that axes of power and oppression can be examined and understood singularly (Bowleg, 2008). According to Collins (2000), intersectionality highlights “particular forms of intersecting oppressions, for example, intersections of race and gender, or of sexuality and nation...intersectional paradigms remind us that oppression cannot be reduced to one fundamental type, and that oppressions work together in producing injustice” (p. 18). Although some scholars have used intersectionality as a way to explore identities and subjectivities, Cho, Crenshaw, and McCall (2013) called for intersectional analyses that foreground power dynamics. They observed, “Intersectionality helps reveal how power works in diffuse and differentiated ways through the creation and deployment of overlapping identity categories” (p. 797). Thus, intersectionality recognizes that systems of oppression operate in interconnected ways, and intersectional analyses seek to uncover and critique political, structural, and cultural inequalities.

Intersectional analyses often center race, gender, and class and less frequently consider disability and age. Although feminist disability studies and feminist gerontology forward the importance of intersectional work, both fields sometimes struggle to enact this practice (Calasanti, 2009; Erevelles, 2011). Therefore, feminist disability studies must engage more intentionally with age, just as feminist gerontology must engage more intentionally with disability. Using an intersectional approach is not just additive, but considers how institutional and structural oppression related to age and disability (as well as race, sex, gender, class, and sexual orientation) come together to mediate the lived experience of old/disabled people in a sociocultural context of ageism and ableism. I argue that an intersectional analysis of successful aging that considers age and disability, in addition to other forms of oppression, demonstrates how the discourses around successful aging have contributed to compulsory youthfulness, which

is interconnected with other compulsory systems (i.e., compulsory able-bodiedness and compulsory heterosexuality).

### **Introducing Compulsory Youthfulness**

The theory of compulsory youthfulness recognizes that anti-aging discourses are entangled with anti-disability discourses due to the inextricable societal linkages between old age and disability. Hence, when people discuss their desire to “remain youthful” or “stay young,” they are referring to more than the maintenance of a youthful appearance; they also want to be able-bodied/able-minded. Thus, compulsory youthfulness is the social mandate to maintain the ideals of youthfulness in regards to ability, memory, health, appearance, activity, energy, sexuality, and social roles throughout the life course, including in later life. In a culture obsessed with beauty, independence, functionality, productivity, and “successful” aging, the idea that to be fully human, one must remain youthful and able-bodied/able-minded throughout the life course permeates nearly all aspects of society.

### **Genealogy of Compulsory Systems**

Before further elucidating the concept of compulsory youthfulness and how it is supported by successful aging discourses, it is essential to acknowledge the genealogy of compulsory systems from which compulsory youthfulness emerges, particularly since these systems are interlocking. Queer theorists and disability studies scholars have discussed compulsory heterosexuality and compulsory able-bodiedness as forms of oppression that dictate specific ways of being, identifying, and living as “normal” and censure, police, and punish people who deviate from these norms.

Rich (1980) coined the term compulsory heterosexuality to describe the assumed male right of access to women sexually, emotionally, and economically. As males benefit from this access to females, this system centers heterosexuality and casts other forms of sexuality as deviant. Compulsory able-bodiedness operates similarly; as Kafer (2003) explains, “Able-bodiedness has been cast as separate from politics, as a universal ideal and a normal way of life, in much the same way as heterosexuality” (p. 79). Thus, compulsory heterosexuality and compulsory able-bodiedness are intersecting hegemonic ideological systems that hold heterosexuality and able-bodiedness as natural, normal, and desirable (McRuer, 2006).

McRuer (2006) observed that the definitions of able-bodied and heterosexual were redundant and defined using oppositional language: “To be able-bodied is to be ‘free from physical disability,’ just as to be heterosexual is to be ‘the opposite of homosexual’” (p. 8). Similarly, old is defined as “no longer young” (New Oxford American Dictionary, 2013). These definitions demonstrate that these systems are fueled by the idea of normalcy (Warner, 1999). McRuer (2006) described both able-bodiedness and heterosexuality as “non-identities,” meaning

that these identities are largely invisible because they are held as the “natural order of things” (p. 12). This characterization aligns with Lorde’s (1984) concept of the “mythical norm” (p. 116) and Garland-Thomson’s (2002) work on the “normate” (p. 10). Each of these scholars is building on the idea that normalcy creates and enforces ideals, and although these ideals can rarely be met, those who cannot meet them are policed and punished. Both able-bodiedness and heterosexuality are held as the standard against which all other identities are measured, thereby promoting the regulation of all lives along notions of normativity. Compulsory heterosexuality and compulsory able-bodiedness denote how the lives of people with diverse sexualities and/or disabilities are regulated through the framework of normative sexuality (i.e., heterosexuality) and ability (i.e., able-bodiedness/able-mindedness). This renders diverse sexualities and disabilities unnatural, abject, and abnormal.

### **Compulsory Youthfulness and Successful Aging**

Similar to compulsory able-bodiedness and compulsory heterosexuality, compulsory youthfulness casts old people, particularly old people who are unable or unwilling to remain young looking and able-bodied/able-minded, as abnormal and deviant. The successful aging paradigm attempted to redefine a “good” old age as one without disability as a way to contest this cultural and societal conflation of old age and disability. However, an intersectional analysis of successful aging demonstrates that the dominant view that associates disability with old age has not been replaced, but rather has become intertwined with successful aging discourses. If to be old means to be disabled, and successful aging is marked by the avoidance of disability and maintenance of high physical and cognitive function, then successful aging is equated with staying youthful and able-bodied. In this sense, successful aging discourses have not redefined old age as a time of health and functionality but rather have encouraged old people to remain as youthful, and thus non-disabled, for as long as possible in order to be “successful” at aging – thereby paradoxically continuing the entanglement of old age and disability, and moreover, contributing to compulsory youthfulness.

One of the reasons the conflation of disability and old age may have persisted despite the intentions of the successful aging paradigm is because successful aging forwarded the concept that able-bodiedness/able-mindedness were ideals for which old people should strive without recognizing that disability can be experienced at any point in the life course or considering how disabled people could fully participate in society and age in ways that are meaningful and empowering to them. Consequently, even people who do fit the norms of successful aging do not want to be old or disabled; they want to be “youthful” (i.e., as young as possible in regards to appearance and activity, and non-disabled). For instance, in her study of able-bodied late-living women in their 90s, Morell (2003) noted that her participants refused to define themselves as old because they were not yet disabled. Although these women were aging successfully according to the traditional model posited by Rowe and Kahn (1998), it is questionable if successful aging

should continue to be held as an ideal if it holds individuals to the unachievable standard of compulsory youthfulness, which casts being old and disabled as diminished states of being.

Furthermore, in a system of compulsory youthfulness, old and disabled people become failures, particularly since successful aging has created a class of old disabled people who are “unsuccessful agers” (Rubinstein & de Medeiros, 2015). This sense of failure is tied to the pressure to be normal, and the framing of non-normative identities as “choices.” In other words, compulsory youthfulness, compulsory able-bodiedness, and compulsory heterosexuality frame being old, disabled, and/or queer as a choice, and a choice that one should avoid if at all possible. McRuer (2006) argued this framing was connected to the rise of capitalism: “In the emergent industrial capitalist system, free to sell one’s labor but not free to do anything else effectively meant free to have an able body but not particularly free to have anything else” (p. 8). Thus, these compulsory systems work together to falsely present certain identities or ways of being as a choice in a system in which there is no choice. Furthermore, given that heterosexual desire, high rates of sexual activity, and able-bodiedness/able-mindedness and are viewed as the “norms” of youth, compulsory youthfulness is further intertwined with compulsory heterosexuality and compulsory able-bodiedness.

Successful aging supports these oppressive ideologies because it frames disability in old age as a result of an individual’s failure to age well. As Rowe and Kahn (1998) noted:

“To succeed in something requires more than just falling into it; it means having desired it, planned for it, worked for it. All these factors are critical to our view of aging which...we regard as largely under the control of the individual. In short, successful aging is dependent on individual choices and behaviors. It can be attained through individual choice and effort” (p. 37).

Thus, for old people, the pressure to make individual choices that retain one’s youthfulness and able-bodiedness/able-mindedness are tightly intertwined, particularly in the context of discourses that mark disability as the norm of old age while simultaneously dictating that one should avoid disability, old age, and thus disability in old age as much as possible. In other words, to avoid becoming “old,” one must avoid becoming disabled, particularly in a culture that does not value and marginalizes both old people and disabled people. These expectations completely disregard people aging with disability, i.e., people who are born with a disability or acquire a disability prior to entering old age (Heller & van Heumen, 2013; Verbrugge & Yang, 2002). Thus, compulsory youthfulness creates an unobtainable ideal, as does compulsory heterosexuality and compulsory able-bodiedness.

Another important connection between the compulsory systems is their connection to neoliberalism and capitalism. As McRuer (2006) noted:

“Neoliberalism favors and implements the unrestricted flow of corporate capital...neoliberal states thus work toward the privatization of public services, the deregulation of trade barriers and other restrictions on investment and development, and the downsizing or elimination (or, more insidiously, the transformation into target markets) of vibrant public and democratic cultures that might constrain or limit the interests of global capital” (pp. 2-3).

Importantly, McRuer (2006) observed a shift in which homosexuality and disability moved from being pathologized to sometimes tolerated by neoliberalism, particularly when the tolerance of such identities served the purposes of neoliberalism.

Successful aging is in many ways a neoliberal concept. As Rubinstein and de Medeiros (2015) observed, successful aging is consistent with neoliberalism due to:

“...Its focus on (a) the individual as the key to social action; (b) its implicit creation of a class of unsuccessful agers, and (c) a failure to provide any explanatory notion, other than individual action, of how [successful aging] might come about” (p. 40).

Thus, successful aging’s emphasis on individual action contributes to the compulsory nature of youthfulness. Rowe and Kahn (1998) also considered “productive behaviors” a part of maintaining social engagement and life, and advocate for old people to be recognized for their “contributions” to society such as volunteerism and unpaid caregiving labor, which also certainly serves a capitalist economy. However, compulsory youthfulness supports neoliberalism and capitalism in a different way, as it encourages old people, as “non-producers,” to become the next best thing: consumers (King, 2006). As consumers, aging bodies are increasingly tolerated. Thus, one of the central ways compulsory youthfulness is promoted and enforced is in the arena of consumerism, as aging people are encouraged to consume products that will keep them as youthful and able-bodied as possible.

Perhaps one of the clearest ways compulsory youthfulness manifests is in the multi-billion dollar anti-aging industry. Compulsory youthfulness is heavily integrated into a cult of consumerism (Ritzer, 2005), through which old people with financial means consume in a futile attempt to maintain status in society. Much of what they consume are products of youth, i.e., products and services intended to mask, reverse, and distract from the signs of old age while simultaneously manifesting displays of vitality, activity, and independence. As King (2006) observes:

“Those few with spending power are invited by moralistic advertisements to lavish it on products that allow them to seem young, or at least look like they try. The spas, golf courses, surfing, dancing, sexual aids, wrinkle creams, hair dyes, and cosmetic surgery...render old people successful retirees who are doing their part as consumers” (p. 57).

The prominence of these intersecting discourses is apparent in anti-aging medicine, which has been heavily criticized by gerontologists, yet appropriates the same rhetoric as successful aging (Flatt, Settersen, Ponsaran, & Fishman, 2013). Increasingly, scientific and medical research aimed at helping people “age well” is focused on preventing disability and slowing or even reversing the aging process.

The pressure to consume anti-aging products and engage in anti-aging procedures affects all people, but is particularly true for old/disabled women, whose bodies are rejected bodies (Wendell, 1996), subject to intense scrutiny, discipline, exclusion, and erasure in a nexus of compulsory able-bodiedness, compulsory heterosexuality, and compulsory youthfulness. These compulsory systems dictate that old women do everything in their power to maintain a body that matches the ideals of these oppressive systems. The “normal” female body is young, able-bodied, slim, and attractive, and these qualities are interwoven. As Calasanti and Slevin (2006) note:

“The body has become central to identity and to aging, and the maintenance of its youthful appearance has become a lifelong project that requires increasing levels of work. Many of the age-resisting cultural practices are the purview of women. Successful aging assumes a ‘feminine’ aspect in the ideal that the good elderly women be healthy, slim, discreetly sexy, and independent” (p. 3).

Although older women often experience a decline in their economic resources, they are still expected to consume products in order to meet these unobtainable ideals. In a recent Time article, “Nip, Tuck, Or Else,” Stein (2015) argued that soon nearly all women will purchase anti-aging cosmetic procedures because of the increased normalization of taking such measures. Furthermore, some anti-aging products, particularly those released in African, East Asian, and South Asian countries, are also marketed as skin lighteners and whiteners (Mire, 2014), furthering the idea that whiteness serves as a beauty ideal for which aging women of color should strive for and consume products to obtain.

Although some people may argue that anti-aging products are more related to the ideal of a youthful appearance than a non-disabled body, women are reporting using anti-aging products in order to avoid being labeled as disabled. In an article in The Guardian, “Do or Dye: Why Women Daren’t Go Grey (Unless They’re Very Brave or Very Young),” Kay (2015) spoke to hair colorist Jo Hansford, who revealed, “I meet women who say their (naturally) grey hair meant they were spoken to as if they were old, and deaf, and an imbecile” (para 18). These women color their grey hair in order to avoid these associations with disability. Thus, these women are aware of the cultural beliefs that equate disability with old age, and their efforts to appear young are directly connected to their efforts to be perceived as able-bodied/able-minded. This phenomenon is a manifestation of compulsory youthfulness.

Aging people are increasingly encouraged to consume anti-aging products and medical procedures in order to be successful agers who remain youthful and avoid disease/disability. Overall, the expectation to engage in consumerism in order to stay as youthful and non-disabled as possible, even in the face of increasing economic vulnerability in later life, highlights the ways in which compulsory youthfulness intersects with other systems of oppression based on race, sex, gender, class, and sexual orientation. The successful aging and healthy aging movements imply that, in addition to being youthful and non-disabled, old people should be White, wealthy, in a heterosexual marriage, retired, and thus capable of seeking leisure in a variety of ways and remaining consumers in a capitalist economy (King, 2006; Martinson & Halpern, 2010). Yet these social mandates ignore the material and social realities of many elders whose gender, race, social class, sexual orientation, and disabilities exclude them from obtaining and maintaining this ideal of aging.

### **Being Old and Disabled: The Influence of Compulsory Youthfulness**

An intersectional analysis of successful aging illustrates how the rhetoric of successful aging has contributed to the system of compulsory youthfulness, in which old and disabled people are made invisible, invalidated, and oppressed due to their failure to reach the unattainable ideal of remaining youthful and able-bodied/able-minded until their death. Analyses of compulsory systems, including compulsory youthfulness, compulsory able-bodiedness, and compulsory heterosexuality, are essential, as the intersections of these systems invalidates groups of people and particular intersectional identities, such as old and disabled people, especially those who are also identify as women, transgender, low-income, or people of color. As intersectional analyses demonstrate, these systems work collectively in a variety of ways that harm people. Thus, the theory of compulsory youthfulness makes important critical interventions in understanding how old age and disability intersect in successful aging discourses and how the power dynamics produced by political, structural, and cultural ageism and ableism influence the lived experience of disabled elders.

For instance, Calasanti (2009) discussed how some old lesbian women have claimed that aging is not as difficult for them because they are less subject to the male gaze; however, many old lesbians have also lamented that old age has made them invisible within lesbian and queer communities. Similarly, scholars and activists have lamented the inaccessibility of queer spaces and events for disabled people (e.g., Ndopu & Moore, 2012; Spade, 2007). Yet there has been little discussion of how to make LGBT communities and queer spaces inclusive for old disabled people (which would lead to the inclusion of non-disabled old people and young or middle aged disabled people as well). Paradoxically, one of the tenets of successful aging is social engagement; yet the discourses of successful aging and their contributions to the system of compulsory youthfulness make achieving inclusion difficult for old, disabled, and queer women.



Similarly, Portacolone's (2013) ethnographic work on precariousness for older adults living alone in the United States highlights the intersections of compulsory systems. Portacolone defines precariousness as "an intrinsic sense of instability and insecurity stemming from a lack of...essential resources" (p. 166), which manifests on micro, meso, and macro levels. Although Portacolone does not directly engage with the rhetoric of successful aging, she noted that participants grappled with the dominant cultural ideologies that successful aging reflects, which emphasize personal responsibility, independence, and self-reliance. Furthermore, despite Portacolone focusing solely on ageism, her participants demonstrate how ageism and ableism intersect and how compulsory youthfulness materializes in their ongoing struggle to live alone. Several of the solo dwellers interviewed emphasized the challenges they faced as old people with chronic illness, injuries, and other impairments. They highlight the difficulty of doing everything (chores, shopping, cooking, paying bills, engaging in hobbies and entertainment) by themselves. Many of them discuss putting themselves in dangerous situations due to their fear of burdening others—for example, one participant drove a manual vehicle home after breaking her foot. Many of the participants who struggled the most were never-married, childless, low-income, and people of color. Their experiences demonstrate how compulsory youthfulness places old and disabled elders in situations in which they struggle to conform to an unattainable ideal of remaining youthful and able-bodied enough to continue living alone without help or assistance from others. If they fail, the consequences are severe – institutionalization or even death. These examples demonstrate how compulsory youthfulness, in addition to other compulsory systems, results in harmful and devastating consequences for old and disabled people.

Beyond the influence of compulsory youthfulness on old and disabled people's everyday struggle for survival, compulsory youthfulness also absolves society of the responsibility to provide for the needs of old disabled people. Successful aging and compulsory youthfulness place the onus on the individual by framing old age and disability as choices and preventable states of being. Thus, if people cannot age while "avoiding disease and disability," "maintaining high physical and cognitive function" and having "active engagement with life," it is the result of their own lack of effort and poor choices they have made. This ideology reflects the neoliberal campaign to "limit the state's responsibility to provide social and other supports for elders and people with disabilities" (Martinson & Berridge, 2015, p. 63). Hence, the movement to lessen government spending and eradicate state support for old and disabled people is tied to the belief that becoming old and disabled is the result of individual (in)action. Consequently, compulsory youthfulness creates a structural and societal context in which old and disabled individuals are blamed for their failure to age without disease or disability and their subsequent dependence on the welfare state. Compulsory youthfulness thereby frames old disabled people as "failed citizens' with only themselves to blame" (Portacolone, 2013, p. 172), and "morally irresponsible and socially undesirable" (Clarke & Griffin, 2008, p. 1092). The emphasis on individual

responsibility also has implications for how old and disabled people are included in society. Under the system of compulsory youthfulness, aging people are included in society as long as they can remain youthful and non-disabled and participate in the economy as consumers. If they cannot maintain these norms, their subsequent rejection, isolation, and even institutionalization is a result of their own failings.

Using compulsory youthfulness as a theoretical lens to understand the experiences of old and disabled people highlights the need for aging frameworks that consider how social structures can promote old and disabled people aging in ways in which they are recognized, included, supported, and able to thrive and flourish. These frameworks will need to be intersectional and interdisciplinary in nature. For instance, working from a gerontological and disability studies perspective, Minkler and Fadem (2002) advocated for further exploration of how physical and social environmental changes may support people with disabilities aging well, and echoed the disability rights movement's call for the provision of adequate resources for disabled people of all ages, which would include funding for expenses such as housing, food, transportation, personal assistance, and community engagement.

Additionally, disability studies is in the midst of grappling with how to address issues related to impairment that are not the result of the environment, such as pain (Patsavas, 2014; Price, 2015). Pain undoubtedly influences aging bodyminds (Price, 2015), and Price's (2015) feminist disability studies ethics of care in relation to the bodymind asks how care might be collective, participatory, and operate in consideration of positions of power. As Portacolone (2013) found, many disabled elders, particularly those who are women, low-income, and people of color, are struggling to make it day-to-day under the belief forwarded by compulsory youthfulness that they must retain their independence to avoid institutionalization. A life course, intergenerational approach to a feminist disability studies ethics of care may push the disability community to consider how the most marginalized disabled elders might be more intentionally included in collective care, and how these elders might also provide forms of care and support to younger disabled people. These ideas demonstrate the multitude of possibilities for coalitional, intersectional work that calls for and leads to economic redistribution, social change, and structural transformation (Spade, 2011).

### **Conclusion**

The discourses on successful aging, with their emphasis on maintaining able-bodiedness/able-mindedness in old age, have not replaced the idea that disability and old age are the same. Rather, they have become intermingled with the discourses that equate youthfulness with able-bodiedness/able-mindedness. In this sense, successful aging has become entangled with anti-aging discourses that mark youthfulness and able-bodiedness as the ideal and encourage people to remain as youthful and able-bodied as possible in regards to appearance, energy, activities, and social roles. Thus, without destigmatizing disability in old age, working

to represent disability as a part of human diversity that may be experienced at any point in the life course, analyzing the cultural, political, and structural forces that influence age and disability, and considering ways people could age well with, and even because of, disability, successful aging models have paradoxically reflected ageism and ableism, and contributed to compulsory youthfulness.

There are numerous possibilities for scholars and activists to continue to think about successful aging and compulsory youthfulness. One option is for research to engage in empirical work to explore how old and disabled people perceive successful aging discourses, and if the system of compulsory youthfulness is evident in their lived realities. One group of people that future scholarship must include is elders who have aged with disability, as they have been excluded from successful aging models from the beginning (Minkler & Fadem, 2002). However, their experiences may help scholars in feminist gerontology and feminist disability studies conceptualize “successful” aging in new ways. Unlike older adults who age into disability, people aging with disability have been confronted with narratives related to dependency and failure throughout their life courses. Many disabled activists and scholars have resisted this rhetoric by developing disability identities, expressing disability pride, and arguing that their lives are actually framed by interdependence rather than dichotomies of dependence/independence. Consequently, resisting dominant discourses and adopting empowered viewpoints may help people who have been disabled throughout our life courses to enter old age with a different perspective than those who age into disability – thereby allowing them to age “successfully” (or on our own terms) because of disability, rather than in spite of disability. Other research could also focus on how other forms of oppression intersect with compulsory youthfulness. For instance, scholars are beginning to consider how successful aging may differ for old Black women (Baker, Buchanan, Mingo, Roker, & Brown, 2015) and old transgender people (Fabbre, 2015), but more analysis of how ageism and ableism intersect in the experiences of these minority groups is needed. Research could also explore how compulsory youthfulness and compulsory able-bodiedness affect disabled people who are young or middle aged. As Slater (2012) noted, “Although the ideal body is always young, the young body is not always ideal” (p. 201). Hence, compulsory youthfulness also influences young disabled people who deviate from the norms set forth by the conflation of disability and old age, and further exploration of this phenomenon is needed, particularly with a life course approach. Elman’s (2014) work on how adolescence has become medicalized as a treatable “condition” may also further elucidate which types of youthfulness are desirable and which are undesirable.

Compulsory youthfulness operates at individual, institutional, and cultural levels to discipline young, middle-aged, and old bodies by enforcing the maintenance of youthfulness and able-bodiedness/able-mindedness throughout the life course. As a theoretical lens, compulsory youthfulness allows scholars to analyze how ableism, ageism, and other systems of oppression intersect, particularly in a cultural context that holds successful aging, in which one remains

youthful and able-bodied throughout the life course, as ideal. Calling attention to how compulsory youthfulness, compulsory able-bodiedness, and compulsory heterosexuality mediate the experiences of old disabled people allows scholars and activists to work toward increasing the life changes of these people, particularly those who hold other marginalized positions, such as women, queer people, transgender people, poor people, and people of color.

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## Research Articles

### Coverage of Aging Well of Individuals Aging with a Disability in Canadian Newspapers: A Content Analysis

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**Abstract:** Aging well is a significant issue for an increasing number of disabled people, yet there is limited attention to what it means to age well from the perspectives of disabled people. This article shares the results from comparative analysis of representations of disability in 4899 Canadian newspaper articles and four policy reports on aging well, and discusses its implications for aging well for disabled people.

**Keywords:** ability studies, IAD, interpretive analysis

#### Introduction

The number of individuals aging with a disability (IAD) is increasing (Klingbeil, Baer, & Wilson, 2004), and aging well is increasingly a matter of concern for disabled people. The media plays a significant role in how the public views certain issues and social groups (Abroms & Maibach, 2008) and, as such, the media impact, what aging well means for disabled people. The purpose of our study was to analyze how Canadian newspapers covered aging well for disabled people. Study findings were compared with representations of aging well for disabled people in four policy reports on aging well, which range from regional to international. The analytical framework of ability studies was used to interpret the newspaper and report findings.

#### Individuals Aging with a Disability

IADs can face significant social challenges related to retirement (Ashman, Suttie, & Bramley, 1995), lack of knowledge of professionals in dealing with IADs (Sheets, 2005), ageism (Sheets, 2005), limited health services (Brown & Gill, 2002), society's unfamiliarity with the discrimination towards IADs (Sheets, 2005), a greater risk of being abused compared to other groups (Walsh, Olson, Ploeg, Lohfeld, & MacMillan, 2010), including being financially abused (Walsh et al., 2010), experiences of isolation (Evans, Evans, & Alberman, 1990), poverty (Klesges et al., 2001; Strax, Luciano, Dunn, & Quevedo, 2010), non-accessible housing (Connell & Sanford, 2001), lack of social support (Jensen et al., 2014), socioeconomic issues (Clarke & Latham, 2014), negative portrayal of aging with a disability (Angus & Reeve, 2006; Stone, 2003), fear of aging which comes with fears of disability and dependency (Angus & Reeve, 2006; Stone, 2003), lack of access to technologies (Kemp, 1999; Thielke et al., 2012) and research gaps in relation to the demographics of IAD (Freedman, 2014). How individuals with

disability age is influenced by many factors; one factor being how the media reports on aging in general, and in particular, how they cover IAD.

### **The Media's Coverage of Aging**

The media can play an influential role in how the public views certain issues and social groups (Abroms & Maibach, 2008). How the media portrays aging - aging well in general, and IAD in particular, influences how the public might view IAD. Studies have examined media coverage of diseases associated with older adults, such as Alzheimer's disease (Kang, Gearhart, & Bae, 2010; Kirkman, 2006); the coverage of issues of health and illness related to Canadian seniors (Rozanova, 2006), and areas of aging such as successful aging (Rozanova, 2010) and active aging (Abdullah & Wolbring, 2013); however, no study has focused on IAD. Our study, which analyzes the coverage of IAD within 300 Canadian newspapers from 1970-2015, provides a first step in addressing this critical knowledge gap.

### **Theoretical Framework**

We interpreted our findings from the newspaper analysis using two approaches. The first approach contextualizes findings by comparing them with the results of an interpretive analysis of four policy reports on aging well that represent regional, national and international scope. The second approach employs the analytical framework of ability studies to interpret and discuss the newspaper findings and the findings of the comparison between the newspapers and the policy reports.

### **The Four Policy Documents on Aging**

Aging well is impacted by local and global factors. We chose two international policy documents that are widely recognized as highly influential, The WHO Framework of Active Aging (from now on referred to as the WHO Report) (World Health Organization, 2002) and the 2002 Madrid International Plan of Action on Ageing (Second World Assembly on Ageing, 2002) (from now on referred to as the Madrid Plan). We also included a Canadian policy document of national scope, the Canada Parliament Senate Special Committee on Aging Report (from now on referred to as the Canadian Report) (Canada Parliament Senate Special Committee on Aging, Carstairs, & Keon, 2009), and Let's Talk About Aging: Aging Well in Alberta (from now on referred to as the Alberta Report) (Chief Medical Officer of Health Alberta, 2013) a report of regional influence and of being influenced by regional considerations. As to how these four documents cover disability and IAD; the WHO Report (World Health Organization, 2002) uses words starting with "disab" n=74 times. The WHO Report uses the term disability, and its variations, mostly within a medical context such as having the increased risk of disability as their Challenge 2 of aging. When they do not focus on decrease or prevention of "disability" they also acknowledge that IAD are likely to be inactive, experience low social status and multiple other barriers and that researchers need to provide policymakers with more evidence on enabling

processes in the broader environment. IAD are also mentioned under Challenge 5: Ethics and Inequities.

The Madrid Plan (Second World Assembly on Ageing, 2002) uses words starting with “disab” n=54 times whereby various items focus on prevention of disability, disability benefit and disability insurance. But the Madrid Plan also calls for the respectful treatment of IAD, policies to extend employability, support for the caregivers of IAD, programs that increase the independence of IAD in rural areas, literacy, numeracy and technological skills training, reduction of poverty, improving the quality of life of IAD, improvement in housing and environmental design, increased access to transportation, empowerment of IAD and to consider the aging of persons with cognitive disabilities as a factor in planning and decision-making processes. Point 90 of Objective 1: Maintenance of maximum functional capacity throughout the life course and promotion of the full participation of older persons with disabilities has over ten action items. The Canadian Report uses words starting with “disab\*” n=27 times. The word disability was mostly used in a medical sense as something to be avoided and something that is a burden to society and oneself. The report for example states: “Fitness is critical to preventing or delaying the onset of chronic diseases of aging, and in reducing the period of disability and dependent living” (Canada Parliament Senate Special Committee on Aging et al., 2009), p.77. The report also highlighted social aspects faced by IAD, such as the greater risk of abuse for women aging with a disability and that seniors with disabilities are less likely to be physically active. The report also brought to attention the VisitAbility project where “anyone with any disability visit[s] your home for a period of three to four hours with no problem” (Canada Parliament Senate Special Committee on Aging et al., 2009), p.88. The Alberta Report (Chief Medical Officer of Health Alberta, 2013) had words starting with “disab” appear n=32 times. Similar to the Canadian Report, the words were mainly used in a medical context. However, the Alberta Report also thematized the social issues one faces as IAD such as lack of access to physical activity, the need for accessible housing and transportation, the need for being able to continue to be part of the community and financial costs one faces as a result of aging with impairments.

### **Analytical Framework**

According to Entman to frame is to communicate an issue in a certain way (Entman, 1993). We use a framing analysis to investigate how IAD are covered within n=300 Canadian newspapers containing the phrases aging well, active aging, healthy aging, successful aging and natural aging. We use the social reality of ability expectation to ground the analysis of our findings and to assess the consequences of how IAD are framed in the aging discourse for IAD contrasting in particular the social disablement framework with the lack of ability framework.

The disability people rights movement coined the term ‘ableism’ to highlight the situation that certain groups expect certain abilities, that certain groups perceive certain abilities as absolutely essential (Various, 2006). The disability rights movement uses the term in ways that others use sexism and racism. In the case of ableism, the focus is on the disablism, the negative treatment by others (Miller, Parker, & Gillinson, 2004) one experiences if one’s body abilities do not measure up to the expectations of others (Wolbring, 2008a, 2008b, 2012). Labeling a body or its functions as impaired is one manifestation of ableism that is questioned by Deaf Culture and the neurodiversity movement (Hladek, 2002; Kapp, Gillespie-Lynch, Sherman, & Hutman, 2013; Runswick-Cole, 2014; Waltz, 2014; Wolbring, 2011; Zeng, 1995). Indeed, “Many disabled people perceive themselves in a cultural identity war with the so called non-disabled people, where their self-identity understanding of being ability diverse and ability variant, as being a culture and not being ability deviant and ability deficient is rejected by many” (Wolbring, 2013), p.189.

Keeping in mind the cultural identity war of who can label a given body and in which way, the question arises how newspapers frame aging well. Newspapers could frame the experience of aging by focusing on the lack of abilities of the body as the body ages (medical/deficiency/negative body frame). Another way of framing could be to focus on the social reality of social disablement or enablement experienced by people aging (social disablement frame). This frame could include thematizing the problem of ability expectations. Indeed, the purpose of the term ableism was to highlight the social disablement linked to the reality of ability expectations and ability privileges such as the ability to work, the ability to gain education, the ability to be part of society, the ability to have an identity, and the ability to be seen as a citizen that comes with a species, ability-typical, body (Wolbring, 2014). Within the social disablement frame the newspapers could cover how ability expectations such as productivity, competitiveness, efficiency and self-sufficiently and other “-ism’s” supported by ableism such as consumerism, superiority-ism and GDP, influence how one experiences aging. Certain ability expectations and forms of ableism can support age-ism (Wolbring, 2007, 2008b) such as the need to be productive, to be able to contribute to society, to be able to work, and to be self-sufficient. However, ability expectations and ableism do not have to be negative but can also be positive or neutral (Wolbring, 2008a; Wolbring & Burke, 2013). One could decide as a society that to live in an equitable society is an ability to be cherished. Indeed one of the main focuses of disability rights and other rights groups is to change ability expectations which in turn would also decrease issues like age-ism.

Given these two main frames (medical and social), the newspaper articles could have three storylines; one purely focused on the medical frame by using terms such as impairment and patient, and by using variations of the term, disability, with the meaning of impairment with no social context; a second story line being a medical/social hybrid frame by still portraying the person in a medical way but highlighting the social disablement the person experiences; and a

third story line could capture a purely social frame by which the person is defined in neutral terms and the focus is on the social disablement.

## Methods

### Data Sources and Sampling

To obtain qualitative and quantitative data on the discourse around aging well and four synonyms (active aging, healthy aging, natural aging and successful aging) as they related to people aging with a disability (IAD) we searched the n=300 newspapers of the Canadian Newsstand Complete Mail from 1970-2015 for “disab\*” in the text of the newspapers (\* assuring that we obtain content related to disability, disabled, people with disabilities and disabled people) with each of the terms linked to aging well (aging well, active aging, healthy aging, natural aging, and successful aging) in the text of the newspapers (August 25, 2015). We obtained n=452 articles through these keyword combination searches. The 452 newspaper articles were downloaded as PDF and imported into Atlas.ti<sup>©</sup>, a qualitative data analysis software. We also searched for terms often used with relation to disabled people such as impairment and patient in the article covering aging well and its four synonyms (October 15, 2015) and the n=489 articles containing words starting with the term, impair were downloaded into Atlas.ti<sup>©</sup>.

### Data Analysis

The research question we investigated was: How was disability and how were IAD covered within newspaper articles containing the phrases aging well, active aging, healthy aging, natural aging, and successful aging? We read the 452 articles keeping in mind the research question and the content of the four policy documents. All articles were read by both authors and coded with the research question and the content of the four policy documents in mind to increase reliability, and differences were resolved during our discussions. Results were evaluated through the four policy documents and the academic literature covering IAD.

### Limitations

This study involved an in-depth content analysis of only English language Canadian newspapers. As such, our findings are not generalizable for Canada or other countries: our data cannot be used to judge other media types either, as we focused only on newspapers. However, we contend that our data can be used to guide future research in this area.

## Results

### Timeline and Source of Coverage of Aging Well

Taking all the aging well phrases (Active aging, +Aging well, +Healthy aging, +Natural aging, +Successful aging) containing articles from the Canadian Newsstand Complete, the

timeline distribution was 1970-1979, n=5; 1980-1989, n=150; 1990-1999, n=2292 and 2000-2015, n=1900 for a total of n=4899 articles.

### **Coverage of Aging Well and the Term Impair\***

Within the n=4899 articles, n=484 articles used words starting with “impair\*”. Of the 896 times words starting with “impair\*” were used in the 484 articles, the phrase “cognitive impair\*” was used n=163; “visual impair\*”, n=563; “brain impair\*”, n=2; “hearing impair\*”, n=33, “mobility impair\*”, n=2; and “memory impair\*”, n=31. Terms related to cognition such as dementia was used n=410 and Alzheimer, n=1211.

We treat as a given that words starting with “impair\*” frame the body/abilities of a person in a medically negative way. As such, using words starting with “impair\*” within a purely social framework is not possible. The question is whether a social hybrid framework was evident within the newspaper articles, meaning that although the body is defined in lack of ability terms, are matters of social disablement also mentioned?

The majority of the articles were news postings on upcoming support group meetings; e.g. the phrase “visually impaired coffee group” was used 167 times. Then, articles covered the appearance of impairment and negative issues linked to the medical aspect of it or to impairment in general, for example, “Almost inevitably, age brings limitations that can impair an individual's ability to live independently," says a sobering Statistics Canada report” (Fayerman, 2005a).

Only n=6 articles covered some social aspect of older adults with impairment; n=2 articles covered the usefulness of technology with one talking about Pearl, a mobile robotic assistant (Ross, 2002), n=1 mentioned about available services (The East York Mirror, 2014), n=1 stated that working in a garden is a non-threatening, non-verbal way to communicate and feel productive (Peterborough Examiner, 2000), n=1 highlighted barriers stating” seniors, too, who experience barriers to activities as part of the natural aging process”, and acknowledging that there are many different types of barriers depending on the person such as doors, signs and the telephone and that there are barriers to “facilities, services and workplaces” (Almonte Carleton Place EMC, 2013) and n=1 wrote about the problem of reaching isolated seniors such as ones with significant impairments (Anonymous, 2010).

### **Coverage of Aging Well and the Term Disab\***

With the words starting with “disab\*” all three narratives could be present. Within a medical framework “disab\*” is used as a synonym for impairment with no social content; within a medical social hybrid framework, the body is seen as deficient but the social disablement is also mentioned; and within a social framework, the body is not medicalized and the focus is on social disablement.

The timeline distribution of the 452 articles containing words starting with “disab\*” was: 1970-1979, n=1; 1980-1989, n=10; 1990-1999, n=38; 2000-2009, n= 210 and 2010-2015 n=202. Eleven newspapers covered disab in more than 10 newspapers: the Winnipeg Free Press with n=82 articles; Times – Colonist, n=35; The Spectator, n=22; The Gazette, n=21; Calgary Herald, n=14; The Times – Transcript, n=12; The Globe and Mail, n=11; The Ottawa Citizen, n=11; Star – Phoenix, n=11; Toronto Star, n=11 and The Vancouver Sun, n=11.

Within the n=452 articles, words starting with “disab\*” were used over 862 times. Most of the times the words were not used to explain content linked to IAD. Within the n=392 times the term disability was used, some of the associated phrases used were: child with a disability, n=92; person with a disability, n=27; disease and disability n=19; born with the disability, n=19; disability tax credit, n=17; person with a disability goes swimming, n=14; sister with a disability, n=4; disability saving plan n=2 disability benefit, n=2 or disability insurance, n=1.

Often disability was used to indicate an impairment with no context linked to IAD such as long-term disability, n=11; intellectual disability n=7; level of disability n=5; physical disability n=4; disability-free, n=4; visual disability n=2, living with disability, n=2; developmental disability n=2; congenital disability, n=2; onset of some disability, n=2. The term disabled was used 184 times; often without any linkage to IAD such as the disabled, n=37 (none linked to IAD); disabled children, n=10; developmentally disabled, n=5.

The term disabled seniors was only mentioned n=6. Various articles reported on the gain of disability (meaning impairment) as one ages (Ball, 2002; Colby, 1992; Henderson, 1986; Long, 2001; Shuttleworth, 2006). One article stated: "A lot of seniors will not admit they have a disability. They call it old age, but when you get down to it they do have disabilities" (Long, 2001). Some highlight that the disability (meaning impairment) threat is not as big as we think it will be (Anonymous, 2012; Elliot Paus & Skrapek, 2013; Fayerman, 2005b; Kelley, 2000; Zimbel, 1998). Avoiding impairments is seen as an indicator for successful aging (Hogben, 1999; Lise Diebel, 2010; Stokes, 2005).

Only n=22 articles covered social aspects. Six articles looked at accessibility (Almonte Carleton Place EMC, 2013; Anonymous, 2015; cole hobson & Transcript, 2012; McArthur, 2014; Meilleur, 2010; Taylor, 2006). Three articles mentioned specifically Universal Design (Anonymous, 2009; Harris, 2012; Moaddox, 1999). One article looked at the poor level of living conditions (The Globe and Mail, 1994) and two mentioned negative stereotypes and lack of knowledge around IAD (Long, 2001; Moorhead, 2000). One article mentioned ageism in relation to “disab\*” stating: “Ageism is discrimination based on age. For example: an older adult can be stereotyped as weak, frail and disabled” (Silverman, 2010). Two articles covered the linkage of poverty and ”disab\*”, where one article stated: "For many of these women, old age is accompanied by chronic illness and disability, which are often the result of lives lived in poverty,

with little or no access to adequate health-care facilities"(Sweet, 1999). The other stated: "Studies in the 1980s into living conditions of seniors and adults with disabilities found hundreds of Ontario seniors living in substandard conditions, some in poverty and with no family"(The Globe and Mail, 1994).

Sometimes the "disabled" were mentioned as a group alongside older adults such as seniors and the disabled, n=6; programs for the disabled and aging seniors, n=3; seniors, disabled, n=3. Pulver for example wrote: "Liberal Leader David Peterson talked about freedom of mobility for older people. He promised the elderly [sic] and the disabled better access to public transportation, lower municipal transit fares and changes in conventional transit systems. 'Without mobility, our seniors and disabled are forced to the confines of their own residences, and they can't get around,' Mr. Peterson said. 'These measures will increase access not just to transportation but to the social and economic life of our province'(Pulver, 1987). (See also (Barrick, 2010; Denton, 2011; Ginabeth Roberts & Transcript, 2012; van den Hemel, 2015).

Only one article covered the relationship between the so called able and disabled older adults, stating, 'It's high time that people like myself who have aged all their life (61 years for me) with a congenital disability (cerebral palsy) and seniors who are aging into disabilities begin communicating with each other,' says James Hunsberger of Waterloo" (Hayes, 2005).

## Discussion

In the discussion section we reflect on the newspaper findings by comparing the newspaper findings with findings from four policy documents on aging that range from international, to Canadian national compared to regional in scope, in order to understand whether the newspaper findings are particular different to other sources or not. We also use the ability studies lens to interrogate the findings.

### Visibility of Disability and IAD

The first issue of importance is how often a word is mentioned. Words starting with "disab\*" were only present in 9.2% of the articles covering aging well; 452 articles in 300 newspapers for 45 years makes 0.03 articles per newspaper per year. Given that some newspapers cover more than the average, many of the 300 newspapers will have no coverage at all. Our findings suggest an invisibility of IAD in the aging well coverage which is a problem for IAD given that readers will not think about IAD in relation to aging well. However this lack of mentioning of disabled people in Canadian newspapers is not limited to the aging well discourse (see for example coverage of food security, (Wolbring & Mackay, 2014) or for that to disabled people per se. The terms "aboriginal people"/"indigenous people"/ "first Nation" were rarely mentioned in regards to active aging (Abdullah & Wolbring, 2013) or other topics of relevance to them (Wolbring & Noga, 2013). Looking at the coverage of social groups in the four policy



documents *disab* and IAD are mentioned comparable to or more than other social groups indicating a difference in focus between the newspapers and the policy documents. Interestingly “aboriginal people”/“indigenous people”/ “first Nation” were mentioned quite a bit in the two Canadian documents but not at all in the two international documents indicating that how social groups are covered can play itself out differently on the global versus national level. As to the numbers the WHO Report (World Health Organization, 2002) uses of words starting with “*disab*”  $n=74$  times which is higher than the mentioning of the terms “aboriginal people”/“indigenous people”/ “first nation”,  $n=0$ ; “gender”,  $n=12$  and the term “women”,  $n=68$ . The Madrid Plan (Second World Assembly on Ageing, 2002) uses words starting with “*disab*”  $n=54$  times which is higher than the mentioning of the terms “aboriginal people”/ “indigenous people”/ “first nation”,  $n=1$ ; “gender”,  $n=24$  and only a little less than the term “women”  $n=61$ . The Canadian Report uses words starting with “*disab\**”  $n=27$  times which is lower than the mentioning of the terms “aboriginal people”/“indigenous people”/ “first Nation”,  $n=169$  and the term “women”  $n=49$  but higher than “gender”  $n=1$ . The Alberta Report (Chief Medical Officer of Health Alberta, 2013) had words starting with “*disab*” appear  $n=32$  times which is higher than for “aboriginal people”, “indigenous people”/ “First Nation”,  $n=12$ , “gender”  $n=1$  and the term “women”  $n=17$ .

### **Portrayal of Disability and IAD**

Even if a word is mentioned that does not mean it is mentioned in positive ways. In regards to how disability and disabled people are framed the newspapers had different options. We found that use of the term disability within a medical framework and the identification of “impairment” as something negative, as something to be prevented, is the prevalent framework in newspapers. Three of the newspaper articles indicated that one needs to have a positive attitude and self-esteem to age positively (Alam, 2000; Anonymous, 2006; Shuttleworth, 2006). How can this positive attitude be achieved by IAD if their portrayal is so medical and negative as our findings suggest? It also contradicts the demand outlined by all four policy documents that the media should present a more positive portrayal of aging and IAD. The Madrid Plan for example states: “Encourage the media to move beyond portrayal of stereotypes and to illuminate the full diversity of humankind,” and “The effects of impairment and disability are often exacerbated by negative stereotypes about persons with disabilities, which may result in lowered expectations of their abilities, and in social policies that do not allow them to reach their full potential” (Second World Assembly on Ageing, 2002). It is indicative of the pervasive embeddedness of ableist thinking that the four policy reports do not see the contradiction between the demand for a positive portrayal on aging and IAD and the medical deficiency focus.

Pervasive ableist thinking is also evident in the sections demanding a positive image of aging. The Canadian report states: “A society that values the contributions and wisdom of the older person makes it easier for an older person to maintain his or her right to make his or her

own decisions” and, “There is an ongoing need to foster a positive image of older Canadians which more accurately reflects today’s seniors and recognizes their contributions to the family, the community and the economy” (Canada Parliament Senate Special Committee on Aging et al., 2009). These two quotes suggest the importance of one’s ability to be a contributing member to society. The use of the ability to be wise segregates people not seen as wise (such as people seen as having cognitive impairments) as a burden to society. The Madrid Plan (Second World Assembly on Ageing, 2002) talks about focusing on older adults as being attractive, diverse and creative individuals that make vital contributions to society, setting the stage for IADs to disappoint. Disabled people are not seen as attractive by the masses and it is questioned whether many disabled people can make vital contribution to society. By adding ability expectations to a positive image the documents nearly ensure that IAD are not part of the positive imagery, short of that we use the supercrip imagery for IAD, an imagery that portrays the person to be super-human to survive against all odds (Harnett, 2000; Howe, 2011; Kama, 2004).

### **Issues IAD Face**

The academic literature highlights many problems IAD face (see introduction). However accessibility was the only issue covered in the newspapers. The four policy documents, and especially the Madrid Plan, covered many more issues faced by IADs; however, all four policy documents missed some critical problems, for example the issue of abuse which is a known issue for disabled people in general and IAD, specifically. The Alberta Report (Chief Medical Officer of Health Alberta, 2013) has a whole section on elder abuse but does not mention IAD as a group in danger of abuse. One would have to read between the lines to see that caregivers were listed as a source of abuse. The Canadian Report covered elder abuse extensively but the report only mentioned once that IADs experience abuse: “Older women are at greater risk of abuse due to increased social isolation, cultural norms, familial status, disadvantage or disability,” linking it specifically to caregivers and institutions (Canada Parliament Senate Special Committee on Aging et al., 2009). The WHO Report also mentioned elder abuse extensively but not in relation to IAD (World Health Organization, 2002). The Madrid Plan also covers abuse extensively and has as an action item: “Sensitize professionals and educate the general public, using media and other awareness-raising campaigns, on the subject of elder abuse and its various characteristics and causes” (Second World Assembly on Ageing, 2002) but does not mention abuse of IAD.

### **Conclusion**

Our findings suggest that readers of the 300 newspapers are rarely, if at all, exposed to IAD in general and even less so to a social frameworks of IAD. Although one could use ability expectations to develop a “positive” imagery of aging well in general and IAD in particular (e.g. by focusing on the ability to live in an equitable society that supports older adults), ability expectation linked to aging well within the newspapers and the four policy documents for the

most part have negative effects on how well IADs age. Most of the abilities linked to aging ill could be classified as abilities IAD lack. Given the overall negative coverage of IAD and the body related ability expectation linked to a positive image of aging, it is not surprising that newspaper articles often mentioned people with disabilities (as a general group) and older adults as two separate entities impacted by a given topic whereby IAD was not the focus. It also might be one reason why the relationship between IAD and other older adults was only covered in one article (Hayes, 2005) and not at all thematized in the four policy documents. There is a need for newspapers and policy documents to focus more on the abilities of IAD to experience their social environment in a positive way and to portray IAD in a positive way. This could lead to greater enjoyment by IAD of the aging process.

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## Research Articles

### 'My Body Feels Old': Seniors' Discursive Constructions of Aging-as-Disabling

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**Abstract:** Social gerontology and disability studies have made similar but separate arguments for ways to study aging and disability, respectively. This article argues for the use of a disability studies perspective to examine seniors' lived experiences. This study conducts interviews with twelve seniors ages 60 to 80 and analyzes the ways they talk about their bodies using grounded theory (Corbin & Strauss, 2008; Glaser & Strauss, 1967). The study finds that seniors characterize aging as disabling and position both identity constructions as negative.

**Keywords:** phenomenology, lived experience, discourse

While conversations in social gerontology and disability studies have much in common, they have not, until recently, informed one another. Chivers (2011) argues that social gerontologists do not fully appreciate disability studies theory and the way it promotes how “different ways of being in the world can be sources of knowledge, satisfaction, creativity, and happiness” (p. 9). Further, disability studies scholars do not examine the elderly (Chivers, 2011). Addressing this gap, Chivers (2011) examines the complex relationship between old age and disability, arguing that social gerontologists have traditionally described “aging well” as aging without disability. Yet this positions disability as negative and does not provide a framework for understanding aging with disability or aging into disability. Instead, Chivers argues, we should examine old age through the lens of disability theory: “It would be exciting to redefine ‘successful aging’ to include seemingly inevitable disabilities as a welcome transformation of self and world” (p. 21).

This study takes up Chivers' call to examine how disability can shed light on the aging body. Separately, the fields of social gerontology and disability studies have evolved in a parallel way, developing similar theoretical lenses for thinking about the aging and disabled body. Specifically, both social gerontology (Calasanti & Slevin, 2006; Coupland, Coupland, & Giles, 1991; Nikander, 2009) and disability studies (Brueggemann, 1999; Davis, 2010; Linton, 1998; Shakespeare, 2010; Wilson & Lewiecki-Wilson, 2001) have examined the ways aging and disability are socially constructed. In disability studies, for instance, the social construction of the concept “normal” creates the concept “deviant,” and thus produces the disabled other in our society (Davis, 2010). Social constructivism led to the development of the social model of disability, which is distinguished from the medical model:

“The medical model has a biological orientation, focusing almost exclusively on disability as embodiment. The social model opposes the medical model by defining disability relative to the social and built environment, arguing that disabling environments produce disability in bodies and require interventions at the level of social justice” (Siebers, 2008, p. 25).

Critiques in both social gerontology (Oberg, 1996) and disability studies (Hughes & Paterson, 1997; Siebers, 2008) have pointed out that social constructivist approaches limit examination of the body's contribution to the lived experience of aging and disability, and that the corporeal body needs to be reentered into the discussion. Siebers (2008) writes, "Some scholars complain that the medical model pays too much attention to embodiment, while the social model leaves it out of the picture" (p. 25). He goes on to write that "some factors affecting disability, such as chronic pain, secondary health effects, and aging, derive from the body" (p. 25), so the corporeal body needs to have a role in the study of disability.

This study bridges the fields of social gerontology and disability studies to examine the aging body from a disability studies perspective. The study conducts interviews with twelve seniors ages 60 to 80 who were recruited from senior center yoga classes in the Midwestern United States. Through grounded theory analysis of interviews, the study finds that seniors construct the aging body as disabled in a number of ways, some of which are more progressive than others. This article suggests an interdisciplinary approach to studying aging, argues for the need to examine a number of metrics to understand aging, and discusses the value in analyzing discourse as a way to examine lived experience.

Re-centering the body within scholarly inquiry about aging and disabilities is not without problems. Several scholars admit that refocusing on the materiality of the body in the analysis of disability and aging could lead researchers back to the medical model (Hughes & Paterson 1997; Siebers, 2008; Twigg, 2004). To avoid this regression, researchers argue for analyzing these phenomena by examining how the body is both socially and materially constructed, and how those poles work reciprocally and continuously to construct the disabled and/or aging body (Hughes & Paterson 1997; Siebers, 2008; Twigg, 2004). In this study, Hughes & Paterson's (1997) phenomenological approach to studying disability is used as a theoretical framework for understanding lived experience. A phenomenological approach, they argue, collapses the Cartesian mind/body divide: "Phenomenology interrogates the 'felt world' in which the carnal, the emotional, the cognitive and the cultural are indistinguishable. 'Lived experience' is itself a concept that refers to the collapse of these analytically separable domains into a perceptual unity" (p. 336). Impairment is a somatic experience while at the same time it is colored by cultural constructions of that experience. Likewise, disability is a social construct that simultaneously is "embodied as 'suffering'" (p. 336).

From a phenomenological position, it is important to understand lived experience as both social and material. Hughes & Paterson's (1997) sociology of impairment allows for the imagining of two continua: disability on a continuum with material on one side and social construction on the other, and impairment on a continuum that has the same poles. These continua intersect in many cases, as most people who experience disability also experience impairment, and vice versa. In this article, the terms corporeal and material are used to talk about

the embodied pole of this dialectical spectrum, and lived experience is used to describe the dialectical space between social constructivism and materiality.

To examine the dialectical space between materiality and social construction, many researchers study discourse about the body and bodily experience (Hughes & Paterson, 1997; Tulle, 2003; Twigg, 2004; Whitaker, 2010). Twigg, a social gerontologist, notes that “age and aging are deeply social,” yet “death and decline are after all central to aging, and they – however socially interpreted – ultimately exist at a bodily level” (p. 70). Still, she writes, researchers need to avoid the medical model, and to do so she argues that

“We need to give weight to the complexity and plurality of social and cultural meanings that have and do adhere to the bodily, recognizing the ways in which the body and bodily experience are constituted in and through discourses. And yet at the same time we need to recognize how these discourses are formed and take shape in a dialectical relationship with real bodies that experience real pain, sickness, and death – as well as other more enjoyable sensations” (p. 70).

Discourse, then, becomes central: researchers can use discourse about the body to identify how the body is discursively represented as well as how the material body influences the discursive representation. This study examines discourse about the body in order to gain a better understanding of the lived experience of aging.

### Methods

This study looks at the ways seniors talk about their bodies by analyzing the interactional dialogue (Benwell & Stokoe, 2006; Davies & Harre, 1990; De Fina, Shiffrin, & Bamburg, 2006; Silverman, 2005) between researcher and participant in one-on-one interviews. Participants were recruited from two senior center yoga classes in the Midwestern United States. Participants’ ages ranged from 60 to 80, and the mean age was about 69. Institutional Review Board approval was obtained by the researcher’s university, and approval to recruit participants was obtained by the directors of both senior centers and by the instructors for both yoga classes. Pseudonyms are used to maintain the anonymity of the participants.

Yoga classes were chosen as recruitment sites because yoga complicates traditional Western notions of the mind/body divide, a complication that may be valuable to understanding lived experience. Identity can be explored through phenomenological, lived experience (Faircloth, 2003; Mitchell & Snyder, 2001; Oberg, 1996; Tulle-Winton, 2000; Siebers, 2008; Twigg, 2004; Wilson & Lewiecki-Wilson, 2001). Oberg (1996) writes that we need to reject Cartesian dualism to understand the lived experience of the elderly: “Dualism is of no help to us. Instead, development narratives should be based on an integrated relationship between body and soul” (p.716). As an Eastern philosophical practice, yoga has as its goal the union of the body and the

mind and the overcoming of Cartesian dualism (Feuerstein, 2003). Since yoga provides people with the opportunity to reconsider mind/body dualism, it might complicate participants' conceptions of mind and body and, thus, aging and identity, in interesting ways.

Volunteers from these yoga classes participated in interviews that lasted 57 minutes on average. Participants were asked a series of questions that focused on seniors' conceptualizations of their bodies, thoughts about exercise, health, and wellness, and the ways they read and write about their bodies. The recordings were transcribed according to an adaptation of Gail Jefferson's (1984) transcription guidelines, and then selections from the transcripts were cleared of false starts, vocalized pauses, and the researcher's continuers for readability in the article.

Grounded theory (Corbin & Strauss, 2008; Glaser & Strauss, 1967) was used to analyze and categorize the data, and a coding scheme was generated to organize the ways participants discussed age. Their discussions of age were organized into ten categories that emerged from the data set. The largest of the ten was the one analyzed here: "participants describe aging as a disability." That category was subsequently organized into four sub-categories:

1. Seniors describe how there are physical things they cannot do because of their ages.
2. Seniors describe how they engage in exercise to combat the physical effects of aging.
3. Seniors describe how they are physically capable in spite of their ages.
4. Seniors describe others as being old and disabled.

While recruiting participants from senior centers, I did not use terms like "senior," "aging," or "elderly," in my recruitment materials to avoid assigning participants a particular age identity. However, I use the term "senior" in this written representation of the study because participants identified themselves as seniors insofar as they joined a senior center yoga class. In the context of this study, "senior" is defined as individuals who participate in events offered by senior centers.

Throughout the interviews, the topic of age only was discussed if the participant initiated it. Recruiting from a senior center yoga class posed challenges, as anyone age 55 and older can participate in the center's exercise classes. Participants' ages ranged from 60 to 80, with a median age of 68. Although the site from which participants were recruited created a younger sampling than many studies on older adults, the data set is still useful because it characterizes participants entering the first stages of older adult life.

### **Analysis**

This section describes how seniors talk about their bodies to equate aging with disability. There is value in looking at the ways seniors talk about their bodies because it draws a connection between the social construction of aging and the materiality of aging. Talking about

the body reveals seniors' lived experiences, which brings the body back into the analysis. An examination of lived experience can help us identify the nuances of the experience beyond guesswork.

### **'I Used to Think Old People Are Just Complaining'**

Seniors equate aging with disability when they argue that there are things they cannot do because of numerical age. Michele, 68 and French Canadian, implies that her numerical age prompted bodily decline. Michele describes when she started to feel bodily pain associated with age: "It's only when I reach 50 then all this came over me, probably from the driven life." She reports that she was caring for several family members, including a mother with Alzheimer's disease, a husband with depression, and two kids, plus keeping up with a full-time job. She goes on to describe various physical problems, including a collapsed arch, pain in her knee, neck, and shoulders, and atrial fibrillation. She says, "So, yeah, my body collapsed (laughs) since I was 55. I'm 68 now." Michele implies that reaching age 50 prompted the deterioration of the body and the onset of conditions.

While Michele argues that her numerical age prompts bodily decline, Elizabeth and Kay describe bodily decline happening in spite of a young numerical age. In each example, numerical age is connected with physical decline, showing that participants view aging as disabling. Early in her interview, Elizabeth mentions that she has read up on the changes the body undergoes while aging. Later, the researcher asks her if she has "experienced any physical changes over time throughout [her] life." Elizabeth responds that she has noticed a number of changes, starting in her late 40s. She says, "I'm not as flexible as I was," and, later, she adds, "Of course, you just chalk it up to, well, I'm getting older." Here, Elizabeth argues that aging has reduced her flexibility, which equates age with bodily decline. The researcher asks her to clarify her statement: "You say you're getting older. What does that mean?" Elizabeth describes how her numerical age, her own physical changes, and the deaths of her parents and her husband's parents have prompted her to think more about aging and mortality. Yet, she says:

"Mentally, I don't feel old. Sometimes my *body* feels old but mentally I don't think of myself as old and 63 isn't that old. But then there are enough physical changes to make me realize that, yes, I am getting older. And then having watched my mother and my husband's father and watching his mother – now it's just, I'm more conscious of it: of the aging process."

Elizabeth lists three potential indicators of age: her mental construction of age, her numerical age, and her physical state. She argues that the first two indicators do not point to old age: she says that "mentally, I don't feel old," implying that the internal self is somewhat ageless as compared with the changing physical body, what Featherstone & Hepworth (1991) call the

“mask of aging.” Second, she argues that “63 isn’t that old,” so the identity marker of the numerical age of 63 does not, in her mind, categorize her as old. Even though Elizabeth’s numerical age and mental state exclude old age from her identity, Elizabeth argues that her physical state marks her as old: “There are enough physical changes to make me realize that, yes, I am getting older.” These physical changes reference her earlier comments that she does not sleep as well and is less flexible than she used to be. Thus, it is her declining physical abilities that mark her as old.

Physical changes are a more powerful indicator of age than numerical age among some participants. Several participants mark old age by the changes they experience despite their numerical ages. Kay describes her worsening arthritis and goes on to say:

“I’m only 66 and I used to think old people are just complaining. Why are they complaining so much? But you start feeling little aches and pains here and there and you think, okay, it’s starting. Now I understand what they were complaining about.”

Kay characterizes her numerical age, 66, as young by using the adverb “only” to describe how she is “only 66.” However, she says that in spite of this young numerical age, she is experiencing old age through “little aches and pains here and there.” Even though she sees her numerical age as young, she identifies as old because of physical debilitation. She further identifies as old by contrasting a former version of herself with “old people,” who she “used to” identify as old because they were “complaining” about physical ailments. Conversely, she now says that since “aches and pains” are “starting,” she now understands “old people,” showing that she identifies more closely with them. Kay’s identity as old is bound up with her material reality, while discursive constructions such as numerical age (Coupland, 2009) do not contribute to an aging identity.

### **‘It Keeps Me from Walking Like an Old Man’**

The second way seniors connect aging with disability is by describing how they engage in exercise to combat what they perceive as the negative, disabling effects of aging. Bob, 68, describes his friends’ reactions to his participation in the senior center yoga class: “Sometimes the guys asked the question, you know, like, ‘What are you doing [yoga]?’ They give you the face, you know, like, ‘You do yoga?’ It’s like, it keeps me from walking like an old man.” Bob layers disability onto aging by stating that a person can perform a bodily movement – walking – in a way that is explicitly and exclusively characterized as old: “like an old man.” In this simile, old age is characterized by walking, but not just any kind of walking; it’s a type of walking that one wants to avoid. Bob shows he wants to avoid this type of physical movement when he says yoga “keeps me from” doing it. Because Bob equates age with a physical movement that he



wants to avoid, he casts both age and this bodily state as negative and disabling. Bob therefore shows that he perceives his use of exercise as combatting the disabling effects of aging.

Other participants also describe exercise as a way to avoid the disabling effects of aging. Sandra, 65, describes the exercise classes she has taken throughout her life, including aerobics, Jazzercise, Zumba, and kickboxing. When asked why she engaged in these activities, Sandra responds:

“Cos I really wanna stay healthy and active. My mom just passed away two weeks ago. She was 98. So we have some pretty strong genes in our family. But at the same time, I think you need to try to ward off arthritis and just some basic things that can get you as you get older.”

Sandra marks old age as a time when one is vulnerable to disabling conditions. She does this by characterizing arthritis and other “basic things” as enemies “that can get you as you get older.” She extends this metaphor by describing how she battles the invading enemy, arthritis, arguing that exercise helps her to “ward off” the condition, among other ailments that can come with age. Sandra characterizes conditions that come with age as debilitating, undesirable states, thus equating aging with disability and positioning both as negative. In both of these examples, participants draw together aging with disability as physical states to avoid, while distancing themselves from those physical states and the identities that go along with them.

### **‘I ... Can Still Lift My Wife Off the Ground’**

Participants also equate aging with disability by articulating that they can do some activity in spite of their age. When participants emphasize the anomaly of being old and also being capable, they articulate the norm that old is equal to disabled, and both conditions are undesirable.

When John, 63, is asked to describe himself, he responds, “Easygoing, active. I never think I’m as old as I am.” The researcher prompts John to clarify what he means by that. He says:

“Being involved with the wetlands and being out on job sites and doing the things that I do. When I was younger I thought, ‘Oh, old people.’ I thought of old people as being old, didn’t do those things. But now I teach scuba diving still. I feel like I stay active and that keeps me feeling younger.”

John articulates the logic that old is equal to disabled, and that since he is abled, he cannot identify as old. John says that he never thinks he is as old as he is because he works with the wetlands and teaches scuba diving, among other activities. This statement implies that people

who are in their 60s should not be able to do these types of activities. He then states that concept directly, saying, “I thought of old people as being old, didn’t do those things.” His statement equates old people with a lack of ability to engage in these activities. He goes on to contrast himself with that image, saying, “I teach scuba diving still.” His use of “still,” implies that he should not be able to teach scuba diving at age 63. By arguing that he is able to do physical activities in spite of being an age he once saw as old, John distances himself from an undesirable identity of aging/disabling.

At 80, Ernest represents the other end of the spectrum of participants’ numerical ages, and he also distances himself from the identity he constructs of aging-as-disabling. When asked how old he is, Ernest responds, “How old would you guess?” Later he reveals that he is 80 and says, “Very few people expect that.” He argues,

“Because I maintain a youthful attitude. I maintain a confidence that appears young. I’m not grumpy. I don’t form frowns. I don’t grouch about things. I don’t bark at people. There’s this certain characteristics that some old people are blamed for. (laughs) Sometimes they have good reason to be grouchy if they’re not being treated properly. I think it has to do with a attitude and demeanor just doesn’t impress on someone who’s older.”

Ernest describes how older people are stereotyped for grumpy, negative attitudes, but then adds that they may have reason to have those attitudes, and that those attitudes are not exclusive to older people. Ernest identifies himself as youthful by distancing himself from an old person’s identity. In the first excerpt, he describes how he is not “grumpy” and doesn’t “form frowns,” and that his positivity helps him to “maintain a youthful attitude.” While the example does not relate to the body, it provides background for the next part of the conversation, where Ernest talks about his body in a parallel way.

The researcher then asks Ernest how he feels physically. Ernest responds,

“I feel great most of the time. I obviously have some limitations, ‘cos I can’t (1.0) But. I know that if I keep moving, keep doing. Can still lift my wife off the ground. There I have physical strength. I still have a lot of energy I can use if I want to. I’m not decaying as it were, except a very small amount.”

Ernest begins his statement as if he is about to list some things that he cannot do when he says, “‘cos I can’t,” and then pauses for one second before restarting his statement. This aligns with much of Ernest’s interview, which is composed of his identity construction as youthful in spite of his age. Like John, Ernest uses the word “still” to say, “I ... can still lift my wife off the ground” and “I still have a lot of energy I can use if I want to,” which implies that one should

assume he should not be able to do these things at his age. By arguing what he can do, Ernest distances himself from the aging/disabling identity, thus tying aging and disabling more closely together.

In both excerpts, Ernest's parallel comparison between his youthful body and old people's disabled physical states could be attributed to the order of the researcher's questions, asking first about his age and then about his physical state. However, Ernest's descriptions of aging/disabling in comparison with his youthful abilities are detailed enough to show that he has thought about this before and that his remarks are genuine to his conceptions of his abilities and identity.

### **'Maybe Life Isn't Worth Living Anymore'**

In addition to seeing aging-as-disabling in themselves, participants make the same conclusion about age and the disabled body when talking about others. This lends insight into one's own sense of aging. For example, Charlotte, 72, contrasts herself with the other participants in her yoga class, marking them as older because they have fewer physical capabilities. Charlotte laments that her yoga class has gotten less rigorous as people with fewer abilities have joined. She says, "I think she [the yoga instructor] was doing a few more things, and I think what she's done is modify, modify, modify for the people that she has in there." Later, she says, "I would like her to go a little faster but then I see that a number of the people in there who cannot. So she has to sorta modify." She goes on to explain that in yoga classes, she, too, can individualize the practice by doing extra moves that the rest of the class does not, and therefore she still enjoys the class. So far in this conversation, Charlotte has not indicated that the less capable participants in the class are less capable because of age. When asked to characterize how the clientele has changed, Charlotte describes how past participants were in better shape:

"They all seemed to me to be in better condition than those people that are there today. Now the gal that was right next to me the other day she was brand new, and she was just a very frail little woman. She had a real difficult time. I mean she couldn't follow the directions. And so [the yoga instructor] kept coming over to help her. And then I've noticed that two or three of the other people that are there are not people that have been there from the beginning."

Charlotte does not directly call the other participants "old," but her characterization appears to go beyond just novice or less capable. The current participants are in worse condition, and one of the participants is "just a very frail little woman." While Charlotte does not use the word "old" to describe this woman, she does use terms that commonly describe the elderly, such as "frail" and "little," and she emphasizes this characterization by adding the qualifiers "just" and "very." By describing the other participants in the class as aging and disabled, she equates these

characterizations, and she also distances herself from the group. This description shows that Charlotte finds the old/disabled characterization as undesirable, and her move to distance herself from it shows that she identifies herself as young.

Participants build their own identities as youthful by describing others as old, and they build a conception of aging-as-disabling in their descriptions. Like most of the men interviewed, John, 63, distances himself from an aging identity throughout the interview by highlighting his physical capabilities. He says that his activities, including his involvement with wetlands conservation and scuba diving instruction, “[keep] me feeling younger.” He reflects on his numerical age as compared with his physical age: “I always thought gee sixties, that’s old. Now that I’m sixties, it’s like, huh. That’s not old. Eighty’s old.” When prompted to define “old,” John says:

“Well I think old is basically when you can’t do the things that you like to be doing. You see people that can barely get around and I feel very blessed and fortunate. I think when people reach that point where they’re not able to enjoy life anymore, I feel that’s old. (laughs) And really there’s nothing wrong with being old I guess. I guess being old is better than not being. (laughs) Although I don’t know. I guess my philosophy would be that if I’m not able to enjoy the life I enjoy, maybe it’s not worth worrying about, not worth being around anymore. (laughs) Not that I have suicidal tendencies or anything. It’s just that I see people that are so miserable and don’t enjoy life, and you wonder, gee, if I couldn’t enjoy good food and a nice glass of wine now, it’s like, well, maybe life isn’t worth living anymore (laughs).”

John equates aging with disability by characterizing the aging of others. He defines old as lacking the ability to do what you want to do and “to enjoy life.” Like the other participants, John describes being old and disabled as conditions he actively tries to avoid.

John takes this attitude a step further when he says that he would rather die than live as old and disabled. His monologue articulates a fear, somewhat masked by the light-hearted tone and laughter, of aging and bodily decline that would strip John of his identity as a physically and socially active adult. The way that his hypothetical narrative invokes tropes of assisted suicide and even eugenics devalues the lives of people who are aging and/or disabled. This example, alongside but perhaps more emphatically than the others, shows how participants articulate resistance to an identity of aging/disabling.

### **Conclusion: The Discursive/Material Construction of Lived Experience**

Analyzing seniors’ discourse about their bodies sheds light on the ways old age is constructed materially and discursively. Throughout this analysis, it is evident that both disability

studies and social gerontology contribute to a nuanced understanding of aging-as-disabling, ultimately revealing that a model for understanding aging must include a number of “metrics” (Coupland, 2009), including numeric age, mental age, and physical age. Additionally, analysis of discourse allows us to study lived experience, and yet we cannot escape discursive construction and focus exclusively on materiality. The metrics that compose “old age” fall along a continuum of discursive and material construction, and it is that dialectical space that must be analyzed to obtain a fuller understanding of aging.

Elizabeth, Kay, and Michele associate numerical age with physical decline, arguing that physical decline is part of what characterizes old age. In talking about these two age markers, the participants draw a distinction between numerical age and material age. Just as Featherstone & Hepworth (1991) distinguish between seniors’ mental and physical ages, the data here show that there is a further distinction between these categories and a person’s numerical age. Coupland (2009) writes that

“Our biological and chronological ageing are, in objective terms, immutable and indisputable, at least until we start to see chronology as a socially created and endorsed meaning system, and until we realise that biological ageing is only one of several metrics that we can impose on ourselves and others” (p. 855).

That Elizabeth, Kay, and Michele describe their lived experiences as aging does not make them older than other participants or mean that their identities are more closely aligned with old age, even though these things may be true. What these discursive constructions of embodiment do, however, is show how “one of several metrics” function within the discursive/material constructions of aging for these women.

In the second and third categories, Bob, Sandra, John, and Ernest argue that aging well means maintaining one’s physical abilities, and several people do that through exercise. Chivers (2011) describes this phenomenon, arguing that our culture promotes aging well by maintaining one’s youthful appearance and physical abilities and avoiding becoming “feeble, frail, ugly, and disabled” (p. 20). The cultural assumption that aging well means avoiding disability is problematic because it demonizes disability. She argues that we should instead apply more progressive disability theories to aging in order to see old age in new, positive ways.

While exercise is almost universally accepted as only a healthy, positive activity in our culture, it can also be seen as an unhealthy support of the medical model. Shakespeare writes that the medical model “[reduces] the complex problems of disabled people to issues of medical prevention, cure or rehabilitation” (p. 268). In the examples of Bob, Sandra, John, and Ernest, exercise is a method of preventing the onset of bodily decline, and thus is a “cure” for the “problems of disabled people.”

Conceptualizing the aging body in positive ways is an important move for social gerontologists. Both social gerontologists and disability studies scholars have called for a need to understand the material embodiment of the populations we study. Siebers' (2008) theory of complex embodiment asks us to "account for both the negative and positive valences of disability, to resist the negative by advocating the positive and to resist the positive by acknowledging the negative" (p. 5). Therefore, the theory of complex embodiment asks us to acknowledge the bodily decline that can come with aging – the decline that Bob and Sandra are trying to prevent, and that John and Ernest argue they are preventing. Even though the cultural trope, "aging well," may have disadvantages for disability studies and aging advocates, it is a construct that acknowledges the negatives of aging, including the potential for painful bodily decline.

The final category shows how Charlotte and John connect aging with disability by identifying it in others, rejecting an aging identity in themselves. Seniors' discursive construction of aging/disabling tells us how they perceive aging in our culture, and their distancing from that identity shows that it is a characterization that they do not (yet) adopt and a materiality that they do not (yet) experience. Instead, they argue that their identity and materiality is young and able, which adds to and complicates our characterization of the lived experience of aging. Other seniors of similar ages admit to the material embodiment of aging/disability, yet these seniors reject it and its potentiality for the near future.

The examples of John and Charlotte complicate the goal of characterizing the lived experience of aging because they call into question what counts as aging. Numeric age, mental age, and materiality are three metrics that are indicators of old age. John and Charlotte do not identify as old, discuss an aging materiality, or indicate that their numeric age qualifies them as being old (John even says that his age, in his 60s, is not old). If "old" is only those seniors who identify as such and experience an aging materiality, then perhaps John and Charlotte are not old and should be excluded from an examination of seniors. While this approach acknowledges the discursive/material construction of age, it may leave out alternative ways that aging people (whether or not they identify as such, and however researchers might categorize them) experience aging materiality. Leaving out people who experience different types of lived experiences at any of these ages may exclude an analysis of the potential "positive valences" (Siebers, 2008) of aging. Seniors in this study only identified the aging body as negatively disabled; but it is possible, through use of disability theory, to imagine other ways seniors might characterize their lived experiences.

A better approach than leaving out seniors like John and Charlotte is to acknowledge that the lived experience of aging is something that can vary from person to person, and to document the ways that participants identify and characterize their ages along multiple metrics. By parsing out the identity of "old" among metrics that fall somewhere within the dialectical construction of

discursive and material, we can complicate the ways “old” is constructed and more accurately represent the lived experience of aging.

Several social gerontologists have called for the use of discourse to document seniors’ lived experiences (Hughes & Paterson, 1997; Tulle, 2003; Twigg, 2004; Whitaker, 2010). This study provides data that characterizes seniors’ lived experiences, showing that discourse is an appropriate tool for better understanding aging. Participants’ discourse about the body reveals both a description of seniors’ bodily experiences as well as discursive constructions of identities that often link up to common cultural tropes.

We need to maintain our focus on the dialectical space between the material and discursive body. Researchers in social gerontology and disability studies made the important move to turn away from the body in order to research its discursive constructions, and now they are making moves to bring the body back into the conversation. To avoid a return to a focus wholly on the body, we must continue to examine the dialectical space between material and discursive construction to get a fuller picture of lived experience.

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### Endnotes

<sup>1</sup> Shakespeare writes, “impairment is distinguished from disability. The former is individual and private, the latter is structural and public” (p. 268). While these distinctions exist, in the analysis, the term “disability” is chosen over the term “impairments.” Traditional notions of disability and impairment separate the body from disability. This article’s phenomenological approach (Hughes & Paterson, 1997) understands disability as including the body and impairment as partially socially constructed. Furthermore, the focus is on lived experience, which is the dialectical space between materiality and discursive construction on both the disability and impairment continua. Within each of these examples, it may be possible to identify evidence of both materiality and social construction of both disability and impairment, yet teasing that out is beyond the scope of this article.

### Research Articles

#### **‘No longer disabled’ – Reflections on a Transitional Process Between Disability and Aging in Switzerland**

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**Abstract:** Switzerland’s social security system categorizes seniors with disabilities according to the onset of the disability. The transitional point between the disability insurance and the old age insurance is retirement. The paper describes the underlying assumptions leading to this transition as well as the ways in which seniors with mobility disabilities deal with its effects.

**Keywords:** social security, Switzerland, successful aging

## Introduction

In 2015, Switzerland was ranked Number 1 on the Global Age Watch Index. Comparing areas such as income security, health status, capability of seniors and the enabling environment for people above 60, the Global Age Watch ranking suggests that Swiss seniors age under comparatively favorable conditions. One of the main pillars of the tripartite Swiss pension system guaranteeing income security is the old age insurance, a solidary social insurance based on redistribution of income from the younger working population to benefit the older retired population (Moeckli, 2012). Political and public debates about this so-called AHV (Alters- und Hinterbliebenenversicherung, lit. old age and survivor's insurance) and the dependency ratio effected by an aging population are relatively vigorous and resulting in ensuing reforms of the old age insurance (Altersreform 2020). Gerontologist Stephen Katz identifies this narrative of the "aging population", describing it as the "burdensome and cumbersome behemoth that roves greedily across fiscal territories, demanding and consuming resources" (2005, p.13), and he sees it as being typical of Western countries.

In this context, the idea of successful aging which posits that the cohort of the 'baby boomers' have the potential to age in an active, healthy and productive way, is an appealing counter-narrative for both state and population. The term, originally coined by Rowe and Kahn (1987), holds the promise that agers which strive themselves for a period of self-fulfillment, healthy lifestyles and activity place less strain on the challenged welfare state and social security system (Rubinstein & de Medeiros, 2015).

Meanwhile, the World Report on Disability (2011) of the World Health Organization (WHO) and the World Bank states that due to the rise of non-communicable and chronic diseases and the simultaneous improvement of biomedical and technological possibilities to prolong life, the percentage of aging people experiencing disabilities is ascending. In Switzerland, there are 317,000 People with disabilities aged 65 and older living at home, 104,000 of which are considered "heavily impaired" (Federal Statistical Office, 2011). While these people may lead fulfilling lives, their bodily conditions and often higher dependency on the welfare state excludes them from the model of successful aging.

In this article<sup>1</sup>, I attempt to examine the complex relationship between disability and aging for seniors with mobility disabilities in Switzerland and their ways of aging in place. By examining the social security system and the transition people with disability make as they become retired, I will show how on a structural level, they are not enabled to age successfully.

## Successful Aging – For All?

The term successful aging was brought to fame by John Rowe & Robert Kahn (Rowe & Kahn, 1987; Lamb, 2014; Katz & Calasanti, 2015). As a physician and a psychologist Rowe and Kahn had a biomedical approach to physical and mental wellness and identified ways with which health could be attained and disease and disability defined through individual action (Rubinstein & de Medeiros, 2015, p. 34). Thus, suspending the then prevalent idea of age equaling decline and replacing it with the possibility of control over one's own health and abilities, the model of successful aging quickly informed public policy on a global scale (e.g. WHO World Health Day in 2012). Today, successful aging has inspired a plethora of ways of thinking about aging – Katz and Calasanti identify successful aging as informing “theoretical paradigms, health measurements, retirement lifestyles, policy agendas, and anti-aging ideals” (2015, p. 26). Additionally, since its rise, successful aging has not only been renamed and adapted into “productive”, “healthy”, “active” or “positive” aging amongst others, but has increasingly been subjected to criticism (Minkler & Fadem, 2002; Lamb, 2014; Katz & Calasanti, 2015; Foster & Walker, 2015). Minkler and Fadem (2002) criticize the paradigm for being excluding of people living with a disability or experiencing other forms of dependency. Anthropologist Sarah Lamb goes one step further by asking the question whether aging successfully carries a conclusively excluding component, as experiencing bodily change and health problems while aging automatically marks a person as less successful (2014). Lamb terms successful aging a “public cultural discourse” which “highlights specific individualist notions of personhood especially valued in North America, emphasizing independence; activity/productivity; the avoidance or denial of decline and mortality; and the individual self as project” (2014, p. 42). She argues for analyses of successful aging, which take into consideration cultural assumptions about both personhood and what it means to age well.

### Methodology

For this article I analyzed data gathered over eight months of my PhD research. I conducted extended narrative interviews and up to three home visits with 24 seniors with disabilities (between 64 and 81-years-old) living in the German-speaking part of Switzerland. Among them were pensioners who experienced polio as children, individuals who experienced brain injuries with lasting effects, persons with paraplegia, and individuals with hereditary diseases or cerebral palsy. The majority of the seniors live with their husbands or wives; only one of the nine men I worked with lives alone. Yet, eight out of the fifteen women live without a partner, pointing to a gendered experience of aging with a disability. I interacted with four couples, where both partners have a mobility disability. In addition, I extensively examined the Swiss social security system and its implications for seniors with mobility disabilities, participated in several conferences and meetings concerning the issues of living at home as a senior with a mobility disability and conducted interviews with various stakeholders and experts in the field. Since participant observation is often a crucial method for understanding participants' subjectivity and perspectives in social anthropology (DeWalt & DeWalt, 2011), I spent as much time as possible

in the seniors' homes, listened to their life stories and recorded their daily routines, watched them perform household activities, went for strolls in the neighborhoods, ate copious amounts of cake and realized how important drinking coffee is in Switzerland as it was offered every single time.

In this article, I focus on the question surrounding what rationale and with which consequences seniors with disabilities are categorized and treated in the Swiss social security system at a transitional point between disability and aging. This transition will be looked at in three different fields: firstly, the structural transition in the social security system; secondly, the socio-cultural models of the body and ideas of personhood justifying the transition in the system and thirdly the perspective and possibilities of action for seniors with disabilities dealing with the transition. Eventually, through the scrutiny of the social security system, the question of whether aging successfully with a disability in Switzerland is enabled will be critically addressed.

### **Who Pays for What? – Structural Transition in Social Security Payments**

Social security benefits for seniors with disabilities in Switzerland are regulated according to the commencement of the disability in an individual's life. Between eighteen years and retirement, the disability insurance (Invalidenversicherung; IV) is responsible for the payment of disability benefits. The most important indicator for the payment of disability benefits are the so called activity of daily living (ADL) criteria, which describe the extent to which a person is able to perform the activities of daily living (Heller & Parker, 2011; Höpflinger & Hugentobler, 2005). If these daily activities can not/no longer be performed by a person themselves leading to a need for assistance, a person is categorized as disabled (Federal Statistical Office, 2009) and may claim benefits, either in the form of assistive technologies, adaptations to the home environment, assistance for the workplace, or in the form of pensions, in case the individual is no longer fit to work. The following first part of the case story of Lina exemplifies the role of the disability insurance during the working phase of an individual's life course.

After Lina O. had a stroke at 57 she moved to L. from Z. so as to be closer to her sisters, who provide her with a feeling of security. Today, at age 67, she still lives alone in the spacious apartment and manages her day-to-day life with hemiplegia on a strict self-imposed schedule: She meditates, goes for a one hour walk and plays the piano daily, striving to maintain her health and abilities. Through home care (SPITEX<sup>2</sup>), food delivery, paid household help and occasional aid by neighbors and family members, she manages her day-to-day life. No longer able to work after experiencing the stroke, she started receiving disability benefits.

Lina, who had a stroke at age 57 was, at the time, categorized as disabled with the ensuing disability benefits granted to her. At 64, the time of her retirement, there was a structural change

of responsibility for benefits granted to her from disability to old age insurance, which at the time seemed to have an impact only on paper.

After reaching the retirement age Lina has been receiving old age pension for the last three years. On our first meeting she was unaware of a change in treatment since the transition from disability insurance to old age pension on her 64<sup>th</sup> birthday. Later in the year, however, heavy rain made the close-by lake flood. The basement of her apartment building was inundated and her electric wheelchair, parked in the garage, broke. Two months later, on our next meeting, she was desperate, because she did not know what to do about her wheelchair which is the gatekeeper to the world beyond her apartment – neither her personal insurance nor the old age insurance wanted to pay for a replacement. Another two months later, she told me that the supplier of her first electric wheelchair had helped her write a request to the disability insurance. The good news: they would pay for it after all. Some weeks later, I received a phone call by an employee of a large Swiss insurance company, asking me about the best way to insure Lina's new wheelchair, they both did not know where else to receive this information from. On my last visit, the new wheelchair had finally arrived and Lina was again able to go for her slow, but steady strolls along the lake.

Lina's story first of all points to the uncertainty regarding entitlements experienced by people with disabilities after changing from disability to old age insurance. They often are not only unaware of who is responsible for providing them with information about their concerns, but also which institutions actually need to cover costs related to their disabilities. Secondly, it shows the importance of financial relief in situations where assistive technologies are vital for participation in daily life. Paradoxically, as the upcoming case of Heinz exemplifies, a similar medical history experienced at age 65 does not lead to the same entitlements.

It was only four months after his retirement from a leading position in the energy sector that Heinz H. had a brain hemorrhage and was left heavily impaired, unable to speak or eat by himself and is now, seven years later, cared for 24/7 by his wife Vreni. In order to bring her husband home from the hospital after rehabilitation, Vreni, a nurse by training, had to adapt the house, install a stair lift and level the thresholds in their family home among many other major and minor adjustments. Upon asking at the social welfare office for possibilities about financial support, she was told that Heinz had bad luck twice; because he was already officially retired at the time of the hemorrhage, the disability insurance would not pay for anything. The social worker suggested that they sell the family home, in order to pay for a nursing home for her husband, and then, with the rest of the avails from the house sale live in a two-room apartment herself. Faced with this option, she decided to do the job of caring for her husband herself in order to not lose their home and be able to stay close together. She started to care for Heinz

herself, with two hours of daily help from home care service, which is paid for by the health insurance.

Paired against each other, the cases of Lina and Heinz point to an important transition. With their 64<sup>th</sup>/ 65<sup>th</sup> birthday women/men in Switzerland officially retire. By entering the retirement age, “disabled” as a status no longer exists and (old) age is now the marker entitling every Swiss citizen to old age pension (Alters- und Hinterbliebenenversicherung; AHV). Individuals who acquire a disability after entering retirement, such as Heinz, (who experienced brain hemorrhage with 65) are therefore not categorized as disabled, because this category no longer exists. The transition has consequences for their entitlement to assistance, for example, while disability insurance covers an extensive variety of assistive technologies, there is only a very limited catalogue of basic devices paid for by the old age pension. The livelihood security, which had been provided by the disability insurance (in various degrees of pensions and amounts of money), is now provided by the old age pension. In cases of individuals who were formerly categorized as disabled, the additional benefits a person received from the disability insurance, especially assistive technologies, can still be claimed, but only to the same degree as before. Through this guarantee of vested rights (Besitzstandgarantie), Lina O. can receive another electric wheelchair if the old one breaks but is not entitled to a different wheelchair if her disability advances or is complicated. Heinz H. on his part is no longer entitled to disability related benefits as his brain hemorrhage happened when he was already 65.

In Switzerland, both disability and old age insurance are social insurances and therefore carry the following traits: (a) the entire (working) population is insured, (b) both insurances are mandatory and (c) the premiums are not only according to risk, but contain an important element of solidarity, that is, a person who earns less pays less, yet regardless of what they had paid, everyone has the right to receive the same merits in case of inability to work (Moeckli, 2012).

The disability insurance exists since 1960 and its main purpose is to “use rehabilitation measures or financial support to ensure the livelihoods of those who suffer from disabilities” (Federal Social Insurance Office, 2016). Thus, the insurance aims at integrating individuals with a disability into the labor market (with (re-)training, support of assistive technologies and personal assistance). If (re-)integration is not/ no longer possible, their livelihood is covered.

The old age insurance is said to stand on three pillars: the first one is the state provision; the second is the professional provision while the third is the private provision (Moeckli, 2012). The focus of this paper is on the state provision for the old age insurance, as the state paid pension can be understood as replacing the role of the disability insurance in terms of covering livelihood.

The two insurances are cut out to support individuals at different points in the course of their lives. However, when a person retires, and therefore transitions structurally speaking from

disability to old age insurance, the status of the disability is bureaucratically “frozen” and transported to the old age insurance. Somehow, the fact that disabilities continually change over an individual’s life course, and thus necessitates changes in support is neglected in the structural transition from disability to old age insurance. Therefore, in order to understand where this neglect is rooted, the underlying assumptions of the two insurances must be grasped.

### **Before the Transition – Disability in Disability Insurance**

With regard to apprehending disability in local worlds, anthropologist Richard Jenkins calls for the scrutiny of socio-cultural models of (in-)competence, the body and connected ideas of human-ness (1999). In his view, bodily norms are connected to expected competences of individuals and show in turn how a society treats those termed ‘incompetent’. In Disability Studies as well as Cultural Anthropology, the investigation of norms and deviance from it are often taken as the starting point to reveal the construct that is disability (Davis, 2006; Barnes, Oliver & Barton, 2002; Whyte & Ingstad, 1995). Thus not only disability, but also the corresponding norm is constructed according to local expectations of personhood. Michael Oliver (1996), for example, convincingly argues that rehabilitation and with that also integration of individuals with disabilities into the mainstream of society is always an issue of a power (im-)balance: the goal of the rehabilitation process, i.e. to become as norm-like as possible, is defined according to the ideology of those in power (Oliver, 1996, p. 104).

In German<sup>3</sup>, the disability insurance is called Invalidenversicherung. Invalide derives from Latin invalidus and means infirm, impotent, feeble, or weak. Furthermore, it carries, the connotation of being in-valid; worthless. Jenkins’ approach asks for an examination of competences, “the capacity or potential for adequate functioning-in-context as a socialized human” (1999, p. 1), in order to understand the expectations placed on individuals within their society. Asked differently, which competences does an individual need to have in order to count as a valid member in the Swiss context? In the case of the “invalid” person in the Swiss state, the incompetence to work is the deviant from the desired norm, namely an independent and self-sufficient person, who can earn his or her own living. The next case study shows what it means to live a life with the pressure of proving one’s own work value.

Edith B. has just turned 64 and lives with Charcot-Marie-Tooth disease. This neurological disease leads to muscle loss, leaving Edith with little muscular strength at her age. She needs assistance in many of her daily tasks, such as getting in and out of bed, showering, cooking, cleaning and other activities. Due to the heritability of her disease Edith was already discouraged from having children at a young age and decided herself she would not have a husband. After working as a home economics teacher for ten years, she became a nun and joined a convent for twelve years. Working in the kitchens and housekeeping of various locations of the religious order led her to live in Germany and even India for a while. When her bodily limitations became

more and more pronounced, they were ignored by her sisters and brothers and she still had to work exhaustively. She was scolded for spilling milk, when actually, the milk can had become too heavy to carry or was made to work for hours standing in the kitchen, when she needed to sit and rest her paining feet. The disappointment of realizing that leading this life would mean the certain end of her strength was only underlined by the fact that she had to face exiting the order with no support and livelihood to fall back on. Trying to find her way back in the “outside world,” Edith felt no longer fit to work and received a full disability pension until she entered pensioner status.

Edith B. worked for as long as possible, expressing the pressure to work fulltime in the monastery in the following way: “...this need to perform... you are a broom, which is used constantly, once it is not important any longer, it can be thrown into a corner and forgotten about. This is what has happened to me, this is how I felt. Performance is what counts and everything else is irrelevant” (Interview EB 23.4.15). Although feeling the need to reduce her workload earlier, she also experienced a strong moral obligation and pressure to work full time. Many other seniors with disabilities who participate in my study feel similar repercussions, now as they are older, despite feeling like they were fit to work at the time. The pressure to work, to prove that despite their disability they could perform as well as their peers, was so high that they had to work against society's' expectations that they were different. This threat of becoming “invalid” is so ingrained, that many of the people who participated in the study tell tales of going to work, even when they were ill, because being incapable of working would automatically be linked to their disability and reinforce the idea that they were incompetent to work. Consequently, their bodies were worn out before retirement age, which often forced them to quit their jobs and to rely on a disability pension. The constant, excessive demand of their bodies during their working years has as they often call it “quickened the aging process”, affected their disabilities adversely, or led to secondary disabilities, e.g. all interlocutors with polio are today experiencing Post Polio Syndrome (cf. Jeppsson Grassman & Anna Whitaker, 2013).

Relinking the pressure to perform in the workplace to Jenkins' call to analyze the local models of personhood, it seems like the Swiss social security system is an ensuing product of, and reproduces the societal order which sees individual diligence and ability to contribute to the workforce as critical not only for humaneness, but also in order ‘to deserve to profit’ from the system.

In line with the idea of integration or rehabilitation ((Wieder)-Eingliederung), the first priority is for an assistive technology to maintain a person's ability to work, the second—regardless of the ability to work—to assist in moving and engaging with the environment and in their self-care (Federal law on the Disability Insurance). A set catalogue of assistive technologies can be claimed to these ends, the need for which must be either attested by a medical doctor or a social worker. As was mentioned above, the assistive technologies paid for



range from (electric) wheelchairs, to lifts for bathing and can even contribute to alterations of individual with disabilities' homes, in order to be accessible. An individual's claim to assistive technologies changes in line with the progressing nature of their disability—until they retire. Before the transition, stating claims and being aware of one's entitlements thus becomes crucial:

Only in the last months before her 64<sup>th</sup> birthday, Edith B. started to realize that she had to sort a few things out and was encouraged by the disability insurance social worker to do so because she would need more assistance in the future in order to stay independent. One of her electric wheelchairs (for outside use) was supposed to be withdrawn from her possession, her bathroom needed to be more accessible and she had to figure out which parts of her care would be taken over by home care (SPITEX) and which paid through assistance money. None of these issues were necessarily pressing at the time, but she would no longer be entitled to the disability insurance, nor could Edith claim them from the old age insurance, despite the progressive nature of her disability.

### **After the Transition – Disability in Old Age Insurance**

With the beginning of retirement in Switzerland and within the regime of the old age pension, only a set catalogue of quite simple assistive technologies are paid for (one hearing aid, a manual wheelchair, and so on). In the case of a newly acquired or a progressing disability, assistive technologies, which support and enable active participation in society, are not funded by the old age insurance. Returning one last time to Edith's case shows how strict this transition is:

Some weeks after entering the status of pensioner, she called the local chapter of Pro Infirmis, the largest organization specializing on people with disabilities, which had been advising her for the last decades and was told that they were no longer there for her. Anything concerning her is now regulated through Pro Senectute, the corresponding organization specializing on issues associated with old age. "One month ago I have turned 64. Apparently, I am now no longer ill, or disabled - I am now just old".

As Edith B. illustratively explains, the Swiss social security system no longer categorizes her as a person with a disability. Jenkins notes that "(in)competence is likely to be entangled with other domains of classifying persons" (1999, p. 3), a fact which can be seen clearly when looking at the transition from disability insurance to old age insurance: while people with disabilities were labeled as invalid by the state in their working years, with retirement this status is obliterated and only one category remains—old (betagt). Following Jenkins' argument, different stages in the life course are defining for the performance of expected roles. Jenkins assumes that "older people may also be defined as less competent, they may become more physically dependent and, perhaps, (...), impaired" (ibid). In contrast to "incompetence" during the working years of a person, the dooming incompetence of the senior population was, for a

long time, understood as the outcome of a linear process culminating in the social role of “the old” (Katz 2005, p. 14). This normalization process, however, evolved further in the course of successful aging models. As was noted above, the aging paradigm has increasingly shifted to understanding senior citizens in two differing age sets: people in their third age are expected to be healthy, fit, active, productive - while only in their fourth age are seniors thought to become less competent, that is frail, dependent and subject to decline (Loe, 2011; Gilleard & Higgs, 2010). It could then be assumed that this understanding of the senior citizen as still contributing to and participating in society and the economy through various activities is also expected from seniors with a disability (i.e. babysitting grandchildren, going hiking, biking and travelling, buying appropriate equipment for these activities, volunteer work, computer courses, going to church, participating in senior citizen’s meetings and so on).

In order to participate, contribute and be active, assistive technologies remain and become increasingly more important for seniors with disabilities. In her work on assistive devices, anthropologist Susan Long (2012) describes the material culture of elderly Japanese people as “silver devices”. Long (ibid) as well as Meika Loe (2010) describe the meaning of assistive technologies for seniors as somewhere between “dependence and independence” (2012:130); “I live here with my things, without them I would be lost” (Interview with KS, 16.04.15), as 75-year-old Karin described her ability to live on her own in a 2-bedroom flat. With the practice of no longer paying for new assistive technologies, the social security system in Switzerland misconceives the fact that a disabled body – as every other ever-aging body – underlies constant changes and processes, leading to changing needs in order to still fulfill a social role. Certain assistive technologies, which had been paid for during the working years, can no longer be claimed once an individual is retired. Edith’s second wheelchair for example, is a case thereof. The underlying rationale behind this cut by the old age insurance is that she no longer needs to participate in society; her role is now to stay at home. In today’s changed social environment where senior citizens are supposed to lead a healthy, active lifestyles, seniors with disability are denied support by the state to “adequately function-in-context” (Jenkins, 1999) and therefore, to age in the same normative “successful ways”, as their peers.

To conclude; the defining difference between disability and old age insurance can be seen in their goals- to integrate and to sustain livelihood on the part of the disability insurance, but only to sustain livelihood on the part of the old age insurance. In the case of the disability insurance, the disabled body is regarded as the deviant from the norm; therefore people with disabilities receive compensation in order to be able to achieve social participation and to perform the expected social role as far as possible. When a person acquires a disability once they are retired, however, the bodily deficits are seen as the norm and the comparison to a “healthy” aged body is not taken into consideration.

Yet, as the following remarks will show, engaging support as a senior with a disability is not straightforward and requires a certain degree of competence and knowledge about the system, as well as strength and a bit of luck.

### Dealing With Transition

In the last section of the article, I would like to trace the ways by which seniors with disabilities circumvent the structural pitfall surrounding the rights to social security support. This is aimed at espousing how seniors manage to make claims from public authorities, in order to receive sufficient support and live an independent life especially as the right to support by the social security is grounded in laws and anything which is not granted within these realms needs to be found in non-institutionalized settings.

After having belonged to an often looked down-upon category which has singled them out for a large part of their adult life, the bodies of seniors with disabilities are normalized before the law and can no longer serve as a grounds to make claims for assistance. With this elimination of the status “disabled”, the social membership of being a disabled citizen is also lost. In anthropologist Adriana Petryna’s (2002) book on negotiations of citizens affected by effects from the Chernobyl disaster with the ex-soviet Ukraine to health claims compensating consequences of radiation, she argues that the system in place is laid out in a way that people are supposed to identify themselves as disabled, by showing as much medical proof as possible in order to make claims and eventually benefit from the compensation for their suffering. One of the main outcomes of her work is the concept of biological citizenship, “(...) the damaged biology of a population has become the grounds for social membership and the basis for staking citizenship claims” (2002, p. 5). Thus, through the creation of a new kind of citizenship, new subjects are formed and as a byproduct, it becomes eligible to be disabled. In the Swiss case of seniors with disabilities however, a category which used to benefit and protect individuals with disabilities and make them as fit as possible for working is retracted. While seniors whose disability has occurred earlier are still entitled to their vested rights, older individuals who age into a disability are not even understood as disabled and never categorized as such.

For individuals aging with a disability, the most effective way to claim support within the social security system is to exhaust the entitlement to assistance while the category ‘disabled’ still exists. As was demonstrated in Edith’s case, this leads to the curious effect that persons with disabilities are preoccupied with organizing and claiming everything they can, before they enter their age of retirement –that is if they are aware of this change in entitlement. This strategy is also advocated by the social workers of the disability insurance, often informing their clientele of the fact that no new claims can be made after the transition to the old age insurance and encouraging them to think about possible future needs for assistance. For those seniors who knew about this and organized additional assistance before it was necessarily needed, the

transition does not have to lead to a change. In fact, the effects of the transition are only noticeable once a change in the ability to perform activities of daily living arises, as was the case for Lina when her wheelchair broke. Others, as the example of Eva below shows, apprehended the transition and are ready to pass on their knowledge.

Eva G., age 71, is the head of the Swiss Interest group for Post Polio Syndrome. She lives with her husband, who is almost 80 years old and who usually cooks lunch and does some of the cleaning, in an apartment in a small city. Eva uses her two small scooters and a wheelchair power unit to move around the house and race to meeting, and she has a stair lift which brings her down the stairs of her apartment building. The Post Polio Syndrome affected her body greatly- her shoulders are damaged, she has vision problems and her walking ability is decreasing, but she is relentless in her work for a better future for seniors with disabilities. With two colleagues, she lobbies, for example, with National Councilors to finally change the law on the limitation of assistive technologies for seniors with disabilities. In daily phone calls and emails with other seniors who experienced polio as children from all over the country, and also seniors with other forms of disability, she advises them on where to receive counseling and financial support, points them to their rights, encourages them to fight for their rights and discloses possible money sources for impending alteration of houses or for further assistive technologies.

A long disability history and engagement with the system, with a social network expanding to various organizations in the field helps Eva to find ways to claim support which is indirectly sponsored by the state sector through performance mandates. Through years of advocacy, by dealing with the disability system and with the respective representatives from different levels, Eva knows the gaps and opportunities the disability landscape offers, resulting in her ability to find financial support whenever she is in need of it. Specialized organizations and interest groups, such as the Multiple Sclerosis Society (MS Gesellschaft) or the wealthy Swiss Paraplegic Center offer their members not only specific practical advice and financial support for their individual needs, but also sustain from excluding categorization according to age. Individuals with rare disabilities or anachronistic ones, such as individuals who experienced polio, however, do not have powerful lobbies and donors and thus need to have more luck in their endeavors to engage support. As the examples of Lina and Edith demonstrate, knowing their rights is one important element; being confronted with a competent or even pragmatic social worker is another. In Lina's case, the first representative of the disability insurance she called in order to receive a replacement for her wheelchair simply shrugged her off. Only on her second, and more formal request was she able to claim what was her vested right. In Edith's case, the legal basis did not foresee a second wheelchair. Her social worker, however, convinced of its necessity, pragmatically decided to grant her this assistance. Other care providers such as health insurances

are further sources of support. In negotiations with these providers, medical proof by doctors is needed in order to state claims.

### Conclusion

As I have shown in this article, an institutional transition in status from 'disabled' to 'old' at a bureaucratically relevant point, but an arbitrary stage in a person's disability history, leads to a confrontation with the social security system within a new, yet less entitling category of citizenship. Through this change in status, wide-ranging financial implications in terms of availability of support for participation in daily life results. The transition thus, has effects on the personhood of individuals with disabilities, as they are once more seen as the 'other' in society. While everyone else is encouraged to age in successful ways, seniors with disabilities are not structurally supported to do the same.

Nevertheless, micro-strategies to circumvent these transitions have been established by seniors with disabilities and are passed on within informal networks, as well as self-help groups. In order to claim their rights as citizens, they have to go beyond the usual citizenship relationship between individual and state, and have to employ pre existing social networks. To conclude, it can be said that the success of navigating the system of the old age insurance at the transitional process between categorizations depends on previous experience, pragmatic decision-making and a well-established social network.

While it cannot be denied that good health and vivid participation in society are also desirable for seniors with disabilities, the normative and absolute paradigm of successful aging is not a helpful way of describing their ways of aging. Firstly, seniors with mobility disabilities are not expected to perform and function according to the rationale of the successful aging paradigm; as per definition, their bodily limitations are working against them. Secondly, successful aging in its normative sense is not structurally supported for seniors with disabilities in the social security system, because with the transition from the regime of the disability insurance to retirement and the ensuing old age insurance, crucial means for integration and participation in society are cut off and can no longer be applied for. Thirdly, successful aging seems so absolute, there is no leeway, no relative individual point from which a person can aspire to age successfully on his or her own terms.

Due to the article's focus on the social security system, the creativeness and strategies of seniors with disabilities with which they manage their daily lives, their resilience to adapt to an ever changing body and the support systems which they have put in place in order to age at home have not been mentioned enough: for it is with the support of the intricate systems which the people who participate in this study have built around themselves, that they do succeed in their day to day lives at home.

## Acknowledgements

Writing this article was made possible by the generous sharing of life stories and day-to-day routines by Swiss seniors with disabilities, the helpful comments by my peers from the Disability & Technology Research Group in Switzerland and Uganda and the insightful and very useful suggestions by the reviewers.

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### Endnotes

<sup>1</sup> The goal of my PhD is to be able to make statements about how seniors with disabilities understand processes of becoming old and disabled, effects of these processes on daily life and on their personhood and how they manage to live in their place of choice for as long as possible. The results, which will be generated through the empirical examinations of case studies of seniors with mobility disabilities, will provide the possibility of extending contemporary ideas and politics (*Leitbilder*) of aging in Switzerland with a view which goes beyond (un)successful aging.

<sup>2</sup> SPITEX: spital- und heimexterne Gesundheits- und Krankenpflege, i.e. organized care outside of hospitals and homes; outpatient care

<sup>3</sup> The focus of my work is on the German part of Switzerland. The French (assurance-invalidité) and Italian (assicurazione invalidità) versions use the same term.



## Research Articles

### The Becoming Subject of Dementia

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**Abstract:** In this paper we analyse the becoming subject of dementia, as it is made to appear within the contexts of nation-building and everyday life. Insights yielded from this analysis suggest the importance of time to recognition of normalcy, and to the meaning of being a person.

**Keywords:** dementia; population aging; normalcy; personhood

“Futurity has often been framed in curative terms, a time frame that casts disabled people (as) out of time, or obstacles to the arc of progress. In our disabled state, we are not part of the dominant narratives of progress, but once rehabilitated, normalized, and hopefully cured, we play a starring role: the sign of progress, the proof of development, the triumph over the mind or body” (Kafer, 2013, p. 28).

“It is not so much that dementia is different from normal ageing; it is that ageing itself is not normal, in the sense that it restricts people from participating in life as they did before. One of the consequences of this articulation of dementia is that it challenges societal life-course expectations. In this sense, it represents an extension of the conceptual shift that has accompanied the construction of AD [Alzheimer’s Disease] as an illness distinguishable from normal old age” (Moreira & Bond, 2008, p. 363).

### Introduction

In this paper we draw from disability studies, cultural gerontology and social philosophy, to critically examine the cultural production of the “becoming subject” of dementia within global policy reports and everyday life. Our analysis uses a social constructionist approach (Berger & Luckmann, 1991), and considers how ways of knowing dementia organize perceptions and experiences of dementia. For example, within contemporary global dementia discourse, dementia is routinely represented as an “umbrella term” that collects and describes symptoms, such as memory loss and disorientation, that can make it difficult for individuals to perform everyday activities, and that result from diseases and disorders that have been found to appear with greater frequency in older adulthood (Alzheimer’s Association, 2016). This way of knowing dementia can be traced to Diagnostic and Statistical Manual of Mental Disorders (DSM)-IV (1994) definition of dementia as:

“Multiple cognitive deficits, which include memory impairment and at least one of the following: aphasia, apraxia, agnosia or disturbance in executive functioning. Social or occupational function is also impaired. A diagnosis of dementia should not be made during the course of a delirium. (A dementia and a delirium may both be diagnosed if the dementia is present at times when the delirium is not present.)”

The DSM-IV definition suggests that dementia is best understood as a multiplicity. Dementia is “multiple cognitive deficits” that manifest in varied ways, and in diverse assemblages with other impairments. It is cognitive, physiological, social and political – affecting functionality across multiple domains. Dementia is simultaneously continuous and discrete. Dementia can co-exist with delirium, an acute “disturbance” that resembles dementia, but is distinct from and endures beyond delirium. In dementia, the disturbance is normalized. The word “dementia” has been erased from the most recent edition, the DSM-V, published in 2013. What was once dementia is now known as a “neurocognitive disorder”, and further divided into “major” and “minor” types. And yet, dementia persists. Despite dementia’s removal from the DSM-V, dementia remains in national and international guidelines and diagnostic and assessment tools used for a range of diseases, including Alzheimer’s disease; many of which are made publicly available online (Siberski, 2012).

In representing dementia as a biomedical problem solvable by medical diagnosis and intervention, the DSM-IV interpretation of dementia aligns with a medical model of disability (Barnes & Oliver, 1993). In contrast, our examination begins with the assumption that dementia, like other disabilities, is a socio-political phenomenon (Titchkosky, 2003). In doing so, we join others who use a social model of disability to expand understandings of dementia beyond an individual biomedical condition, towards recognition of dementia as a social and political identity shaped by disabling processes and social orders (Baldwin, 2005; Bartlett, 2014, 2000; Bartlett & O’Connor, 2010; Boyle, 2014; Burke, 2008; Chivers, 2011; Downs, 2002; Innes, 2009; Kitwood, 1997). A focus on relationality, and the co-production of disability and non-disability is central to a social model perspective, as articulated by Goodley and Roets:

“The social model of disability has turned attention away from a preoccupation with people’s impairments (and the associated ‘consequences’ on everyday activities), and instead focused on the ways in which disability is created – through the social, economic, political, cultural, relational – and psychological – exclusion of people with impairments” (2008, p. 241).

Goodley and Roets (2008) also note that within disability studies, the social model of disability and the language of impairment are themselves politically charged. Critiques of the social model suggest that it ignores the realities of impairment as they are lived and experienced by disabled people. Our analysis counter argues that medicalized constructions of impairment are

reshaping the meaning and experience of the social. This is evidenced in the DSM-IV definition of dementia, which lists impairment to “cognitive”, “social” and “occupational” “functioning”; implying equivalence; and which frames them individually and collectively (in terms of their interactions and relations with one another) as biomedical subjects (specifically, subjects of psychiatry).

### **Dementia, Personhood and Abnormal Aging**

Dementia is a Latin word that means “away” or “out” of “mind” or “reason” (George, Whitehouse, & Ballenger, 2011, p. 419). Much of the current literature on dementia suggests that dementia is characterized by an impairment of the self that affects self-experience (Summa & Fuchs, 2015), self-reflection (Boyle & Lorna, 2015; Boyle, 2014), self-narration, and social self (Downs, 1997; Kitwood, 1997). What is imagined to be suffered in, and in-relation-with, dementia cannot be explained solely by medicine. What is also suffered is an expectation of living with what Sabat (2008) refers to as “spoiled selfhood”, both of the person with the dementia diagnosis and this person’s intimate others. For Sabat, “spoiled selfhood” occurs when interpretations of behavior emphasize pathology, and the individual loses control over self-representation.

The foreword to The World Alzheimer Report 2015 opens with the assertion that, “Today, over 46 million people live with dementia worldwide, more than the population of Spain. This number is estimated to increase to 131.5 million by 2050” (Alzheimer’s Disease International, 2015, np.). The report proceeds to share facts that illustrate the scope and critical mass of dementia as a global issue by comparing dementia to both countries and corporations:

“Today, the total estimated worldwide cost of dementia is US \$818 billion, and it will become a trillion dollar disease by 2018. This means that if dementia care were a country, it would be the world’s 18th largest economy, more than the market values of companies such as Apple (US\$ 742 billion), Google (US\$ 368 billion) and Exxon (US\$ 357 billion)” (Alzheimer’s Disease International, 2015, foreword, np.).

Projected increases in the prevalence and incidence of dementia are based entirely on projections of population aging (Alzheimer’s Disease International, 2015, foreword, np.).

Population aging is now occurring in almost all countries in the world, and has been described by the United Nations as, “Poised to become one of the most significant social transformations in the twenty-first society” (2015, p. 1). Mullan (2002) observes that while current concerns about a “demographic time bomb” can be traced to the 1970s, it was only in the new millennium that the fear of population aging and its implications for individuals, societies and politics took root. The baby boomer cohorts had drawn attention to trends in aging, but at this point the focus was not primarily on the prevalence of older adults. Rather than a “time

bomb”, declining fertility rates and aging populations were viewed favourably as an indicator of well-being and a sign that countries were headed in the right direction. As Mullan asserts, “Old age was seen as an opportunity rather than a penance” (2002, p. 80). Mullan also suggests that, “The main determinant for the rise of concern now is not population trends in themselves, but that the ageing preoccupation is a suitable manifestation for contemporary anxieties – fears with different, non-demographic roots” (p. 78). To understand the non-demographic roots of current concerns about aging, as a ‘becoming subject’ we consider how ideas and images of dementia illustrate a shift in how the subject (or citizen) is understood within the Western political imaginary.

The first national dementia strategy was introduced in Australia, followed by the UK - England and Scotland, and one is currently in development in Ireland (Alzheimer’s Society of Ireland, 2012). Seven of the Group of Eight (G8) highly industrialized nations have dementia strategies in place, the only exception being Canada. Such strategies include recommendations and approaches that appear to embody the principles of an emerging paradigm within dementia care: person-centred dementia care. This paradigm rests on Kitwood’s (1997) theory of personhood as a relational accomplishment that can be distinguished on the basis of a perception of “human life as interdependent and interconnected” (p. 8), a “special form of intimacy”, a “going out towards the other ... a journey into uncharted territory” (p. 10). The focus on the interaction between people with dementia and their carers has been recognized as a significant contribution made by Kitwood’s theory of person-centred dementia care (Baldwin & Capstick, 2007). However, a focus on interactions and relational approach does not protect against disablism, as we explore below.

Kitwood (1997) suggests that prioritizing personhood over dementia is a strategy care professionals can use to combat the dehumanization of “severe disability” – for people living with dementia diagnoses, and for themselves (1997, p. 14). The logic that supports this strategy makes the assumption that dementia offers an occasion for nondisabled people to reflect on their own anxieties concerning the probability that in time they too could become “demented”. Within the person-centred philosophy advanced by Kitwood, anxieties concerning dementia that construct dementia as a reminder of the precarity of personhood are best understood as symptoms of a distorted experience of time. The logic of this philosophy parallels the logic of “temporary able-bodiedness” (TAB) (Breckenridge & Vogler, 2001). It rests on the assumption that within a context of population aging, in time anyone could become someone-with-dementia, and the call to promote self-determination for all, lest risk becoming someone who shares the fate of presently dehumanized others.

Further, according to Kitwood, anxieties regarding dementia are troubling primarily because of the way they can deplete an individual’s “stock of learned [adaptive and experiential] resources for [future] action” (1997, p. 15), leading to a less developed personality (and by

implication, a person of an inferior type). Recognizing and prioritizing the personhood of individuals with dementia diagnoses are represented as techniques the nondisabled individual can learn and employ in the interest of securing a more highly developed personality and authentic sense of self.

Despite the on-going proliferation of new types of dementia, Alzheimer's disease remains the most common form of dementia (Alzheimer's Association, 2014). Basting (2008) contends that popular understandings of Alzheimer's disease as a "horrifying experience" (p. 212) are shaped by the national imaginary, and its ideological and mythologies concerning the natural citizen. Alzheimer's disease represents a threat to national identity, by projecting a future undoing of the nation's history and biography – its becoming story. As Basting asserts, "In a country that declared its 'independence' and that prides itself on its bootstrap success stories and rugged individualism, Alzheimer's disease is seen as the ultimate nightmare" (2008, p. 212). Globalization has meant that such assumptions are not restricted to Americans, and can be observed within global policy recommendations.

A notable example is found in the World Health Organization and Alzheimer's Disease International's *Dementia: A Public Health Priority*, which frames dementia primarily in terms of cost, stigma, suffering and loss (2012, p. 90):

"The costs of dementia are estimated at US\$ 604 billion per year at present and are rising more quickly than prevalence of the condition. The impact of dementia on socioeconomic conditions worldwide is enormous. Furthermore, dementia is highly stigmatized and universally feared, with studies suggesting that it is strongly associated with suffering, disability and economic loss at all stages of a person's journey through dementia."

In this report and others like it, rises in the number of older adults and in the prevalence of dementia are represented as co-constitutive problems. The nature of their relationship is constructed as self-evident, despite explicit claims that the physiological and psychosocial changes associated with dementia are distinct and ought not be confused from changes associated with "normal aging". Yet, nowhere is normal aging explicitly and unambiguously defined.

Within discourses of population aging, dementia is represented as a natural consequence of "abnormal aging". The meaning of "abnormal aging" operates across at least two registers: it signifies the aging-related pathologies that produce dementia as a physiological condition; and, on a more macro level, it also signifies current and projected demographic trends that challenge normative understandings of the life course. Although population aging is increasingly recognized as a global issue, it is most pronounced in developed countries. What is more, as is the case with a whole host of other psychiatric diagnoses, the diagnostic construct of dementia is

a Western invention, and not culturally universal (Timimi, 2014). Thus, abnormal aging can also be understood in a third way, as an effect of modernization and development. The concept of abnormal aging conditions the possibility of Western power's recollection, reflection and re-enactment of what is essential about being Western, its "self". Countries in which dementia is "on the rise" symbolize a nodal point in understandings of abnormal aging. The convergence of knowledge of abnormal conditions and non-normative trends produces something new: a conception of "normal aging" as a process that includes, is shaped by, and interacts with abnormalcy, without the abnormalcy becoming normalized.

A privileging of the uniqueness of persons, and a focus on eradicating the stigma associated with dementia are central to calls for the development of global dementia strategies and networks, comprised of partner organizations with community-based and international scopes. Under the auspices of improving the quality of life of persons living with dementia and their caregivers, dementia strategies and networks construct a divided image of dementia as a becoming-subject that is simultaneously natural and political; a biomedical condition and global economic burden pushing nations and their citizens to the brink of crisis. This divided image of dementia is productive of ways of knowing and relating to dementia as temporal thing – indicative of a phase, stage, or episode - that can be managed so as to promote assurance, optimize investments, maximize experience, and above all, minimize risk.

Representations of dementia as a temporal thing are evident in health and policy research population projections on the exponential growth in the prevalence of dementia. Such projections tend to be characterized by two common and interrelated themes. The first theme concerns the use of screening practices and technologies at the individual level, to identify dementia early in its progression, before persons with dementia become too different from persons without dementia. This theme is dominated by a staged understanding of dementia as a degenerative condition characterized by measurable cognitive decline. It is exemplified in Mild Cognitive Impairment (MCI), a clinical diagnosis that also serves as a means of formally classifying someone as being at risk for developing Alzheimer's disease or dementia.

MCI is characterized by observable changes in memory recall, language, attention and spatial navigation, which exceed what is expected of normal aging, but do not interfere with the activities of daily living. MCI is described in ways that suggest it too can be imagined as a stage in what some educational programs and advocacy groups refer to as the "dementia journey" (Alzheimer's Disease International, 2013), as "predementia" - a prologue or forerunner of a dementia to come (Chertkow, Feldman, Javoca, & Massoud, 2013). Although research evidence suggests that people with MCI are at a higher risk of developing dementia than the general population, it is inconclusive with respect to the actual extent of this risk, with significant differences noted across populations (Langa & Levine, 2014). Moreover, not only may people diagnosed with MCI not develop dementia, they may even experience improvements in cognitive

function (Smith et al., 2013). Considering that there is no effective medical treatment for MCI (Karakaya, Fuber, Schroder, & Pantel, 2013), its currently privileged status within clinical discourses of dementia may have more to do with the role that MCI plays in marking a transition towards dementia; of marking its becoming, and making it more amenable to being monitored. MCI provides a rationale for calls for screening and early identification for a condition that has no cure (dementia), and doing so in the absence of formal diagnosis. Whether or not dementia develops may be tangential to the broader goal of documenting the dementia journey and in the process, producing objective knowledge about normal aging.

Discourses of MCI organize interpretive relations to the appearance of dementia as an opportunity to narrate the ‘origin story’ of Western global power. People are living longer because of advances in science, technology and social order introduced in and by Western modernity. Although currently there is no cure for dementia, one needs only to look to the past successes of Western science to know this will not always be so, and that it is only a matter of time before there is a cure. Until then, in the meantime, we need to document our failures. Doing so will help us to understand future successes.

MCI is exemplary because it affirms the Western modernist commitment. It invokes the becoming subject of dementia haunting national and global reports on population aging. As such, MCI simultaneously activates and addresses aging-related anxieties, throwing the ameliorative power of modern science into relief. Further, its liminal status as marker of the “the edges of normalcy” (Titchkosky, 2014) and normal aging positions it as a driver of innovation, yet not responsible for any consequences of innovation. Thus, MCI serves as a harbinger of new taxonomies of difference that could be used to develop systematic understanding of normal aging. MCI is exemplary in one other way. It produces dementia and people with dementia as inessential to understanding dementia. MCI offers a way to develop knowledge about dementia using information from people who do not have dementia, but who could one day. As a result, people living with dementia in the here and now, especially people identified as having “moderate” and “late stage” dementia, become less essential to how dementia is known. Dementia, positioned in relation with MCI, makes dementia appear less timely and attractive as a subject.

The second theme concerns the use of screening practices and technologies to monitor trends - to document and follow what kinds of issues dementia is becoming within, and for, individuals, families, communities, industry, systems, and countries. This theme is embodied in recommendations that nations enhance data collection related to dementia, and monitor trends (Prince, Bryce, Albanese, Wimo, Ribeiro, & Ferri, 2013, p. 63).

Policy recommendations related to the early identification and documentation of dementia to track its development include the caveat of that monitoring will be challenging in non-Western

and “developing” countries where professional medical knowledge of dementia is lacking, or where the meaning of dementia may not yet have taken hold in the minds of citizens (WHO, 2012). This theme is dominated by a modernist understanding of development, which is defined using the World Bank’s categories of low, lower-middle, upper-middle, and high income, to stratify countries according to their Gross National Income (GNI) per capita. Such recommendations can also be read as evidence of the ways, “Neoliberal economic and socio-political rationalities urge responsible individuals to control their health not only for their own sake but also for the socio-economic good of the nation” (Erevelles, 2011, p. 79).

What dementia means and how dementia is understood and experienced is also informed by national reports, such as the 2010 Alzheimer Society Canada’s report, *A Rising Tide*. *A Rising Tide* opens with the assertion that the current 500,000 Canadians with Alzheimer’s Disease or related dementias will grow to 1,100,000 within a generation. Despite an acknowledgement that health promoting lifestyle changes and preventive practices have been associated with a decline in the prevalence of a number of specific types of dementia, the report reminds readers that this does not change the course of population aging or the fact that dementia is “on the rise”. It also forecasts that “within a generation” there will be a similarly exponential growth in financial costs to national economies - projected to increase from approximately \$15 billion to \$153 billion, and in the erosion of individual caregivers’ time –231 million hours to 756 million hours (Alzheimer Society Canada, 2010). Within this report and other texts like it, facts about prevalence and demography shape more than the cost of dementia care and services. Strategic references to a rapid and global growth of loss that can be expected to be experienced within the reader’s life time (i.e., “within a generation”) inform what kinds of questions can be asked in the study of dementia – questions concerning the possibilities and limits of (inter)national prosperity, sustainable (self)governance, social and individual breaking points and points of no return.

The title of the Alzheimer Society Canada (2010) report evokes the (in)famous Wall Street proverb, “The rising tide lifts all the boats,” which coincidentally US President Kennedy also used in a speech to mobilize support for US intervention in Europe during the Cold War. This expression highlights the need to focus on macroeconomic growth (raises in a nation’s Gross Domestic Product/market valuations over a given period of time) as good for everyone, and threats to the status and prosperity of the group as a whole as detrimental to each and all. One of the major criticisms of this view is how, in absence of appropriate, targeted policies some may flourish while others run aground. In his narrative of the development of *Rising Tide* report, former Chief Executive Officer of the Alzheimer Society of Canada (2007-2009) Dudgeon (2012) suggests that recognition, regulation and the exercise of restraint on the part of governments and individuals are required if the rising tide of dementia is to be an opportunity and not an obstacle to Canadian society. Canadians need to take notice of dementia, and do so in a productive way, lest others (Europe, the United States, but also other countries that do aging well) may profit while Canadians are run aground or amuck. A central premise of *Rising Tide* is



that while Canadian governments, communities and individuals need to do better than well, they also have to be careful not to rock the boat.

Shifting our focus from the national to the global, one observes a similar logic in the Organization for Economic Cooperation and Development (OECD)'s 2013 brochure, *Addressing Dementia: The OECD Response*, developed for the G8 Summit held in London in 2013 with the "goal to place dementia at the fore of international collaboration". It opens by citing the history of the OECD and its connection Marshall Plan or European Recovery Program, an American initiative comprised of "34 member countries committed to democratic government and the market economy" developed to aid and rebuild Europe following WWII in order to prevent the spread of Soviet Communism via collaborative projects that focused on modernization, free trade and stabilizing/securing European prosperity. The focus of the brochure is on modernization, free trade and stabilizing/securing European prosperity. In the brochure dementia is described as a "major health burden with high social and economic costs"; a degenerative and deadly condition that "hospitals are still unprepared to deal with"; difficult to diagnose and treat effectively – a risk; a challenge and an opportunity - to promote modernization and advances in information and technologies (Big Data); global surveillance (sustainability of data sets, exchange and access to data, linkage, quality and efficiency, capacity building). Although Europe and its allies had apparently triumphed over total death and dissolution, new threats emerged from within Europe that threatened democratic self-actualization.

In the remainder of this paper, we turn our attention of a consideration from the macro to a narrative analysis of a micro-interaction: a joke once told as a truth. In doing so, we trace how assumptions about normalcy what some public health commentators and demographers have referred to as the "grey tsunami" (Simpson, 2014) organize relations to dementia within interpersonal relationships and everyday life.

### **Pulling the Plug on Normalcy**

During a visit to my doctor, I asked him, "How do you determine whether or not an older person should be put in an old age home?"

"Well," he said, "we fill up a bathtub, then we offer a teaspoon, a teacup and a bucket to the person to empty the bathtub."

"Oh, I understand," I said. "A normal person would use the bucket because it is bigger than the spoon or the teacup."

"No" he said. "A normal person would pull the plug. Do you want a bed near the window?"

You can find this joke on the Internet when searching for resources related to the topic of dementia (see for example, Josline Diabetes Centre, 2008). When we came across it, it was not our first encounter. A woman who lived with her mother, who had a dementia diagnosis, first told it to us. This daughter was struggling with siblings to keep her mother at home. Her struggle

was conditioned by her current status as a co-resident in the family home, which stayed in the family as long as her mother stayed at home. The daughter said a doctor had subjected her mother to the bathtub test, and her mother gave the right answer – “pull the plug”. One could suppose it did really happen, although one could also suppose that it may have been the daughter’s way of making a connection. Perhaps she also read it on the Internet when she was seeking information and support; something to hold on to and use to make sense of where she found herself, with her mother; and what her mother might have said, had someone had asked her what she would have done. In describing this exchange between her mother and the doctor, this woman also shared that her mother is a wonderfully funny lady who was always telling jokes. That was why it was so easy to believe the truth of this joke, this brainteaser that could be someone’s experience and lived reality. It really could have happened, it even might have. In sharing this story, this woman told us that normalcy is something that has to be recognized for it to be real. Given the chance her mother would know the answer, and make the right choice. She would pull the plug, and the professional putting her mother’s normalcy to the test was the one who actually needed the bed near the window.

What is it that makes this choice the right choice, and the mother recognizable as a “normal person”? To understand, let us return to all of the options we have available to us and begin with the teaspoon. There is an agony to the image of a person using a spoon to empty a tub. The time and expenditure of energy involved in emptying a tub of water with a spoon makes this approach appear not only laborious and excessive, but even as a self-defeating task. This alone would logically lead to the exclusion of the spoon as the tool to get the job done in the best way. The choice of the spoon embodies the relationship to uncertainty characteristic of a spoiled self. This relationship is epitomized in the infirmed cogito of Descartes’ Second Meditation that understands it thinks and exists, but lacks insight concerning its limitations and finitude. As Ricoeur says, “Left to itself, the ‘I’ of the cogito is Sisyphus condemned, from one instant to the next, to push up the rock of its certainty, fighting the slope of doubt” (1992, p. 9). Imagining our choice in this way also makes it possible to imagine the tub as a spatiotemporal schema that reveals a relational order. Everyone knows no one should choose the spoon. And yet, the spoon remains as a choice, which also serves as a diagnostic tool. Like the spoon, current diagnostic practices demarcate relations of truth and/or error. They serve as constitutive marks of the limits of human agency.

Our second and third choices are the bucket, and pulling the plug. The bathtub test reveals that what is at issue in human agency is evaluation: how humans evaluate a situation and act in the face of uncertainty. What makes pulling the plug the best choice is its time-efficiency<sup>1</sup>. The bucket is not only more time consuming, but also more labour intensive than pulling the plug. It won’t get all of the water out of the tub; there will be traces of water left. Where will the water moved using the bucket go? The plug solves the problem cleanly and completely.

Following Taylor (1985), one might say that there is a utilitarian logic at work in normative diagnostic evaluations of dementia. We want to be able to calculate the right evaluations and “reduce practical reason to calculation” (Taylor, 1985, p. 17). To do so, we need to get rid of the strong and weak evaluations (the spoon and the bucket), and take a big picture view of the situation in its totality. Knowing to pull the plug rests on the assumption of a pre-existing infrastructure that can support the water’s removal.

The bathtub test suggests that the realness of dementia comes into view in situations where people need to weigh alternatives. It also suggests more. The joke illustrates a normative understanding of rationality as something that can be measured in terms of losses and gains. While pulling the plug appears as though it is the radical choice, it could also be understood in terms of preference. Although it was not proffered in a list of choices, pulling the plug resides in the common stock of knowledge. The criteria for knowing how to respond are present as part of the horizon of experience that makes tests of normalcy a sensible and worthwhile human engagement. From within this horizon, the assertion to pull the plug does not necessarily have to be creative. It can be caustic, dismissive. Of course you pull the plug.

The difference between the spoon and the bucket elicits the desire for a third way, and an implicit recognition of what Ricoeur (1992)<sup>2</sup> refers to as the third person, yet unarticulated but no less present. In lieu of framing the choice to pull the plug as a radical choice, a choice made without criteria, we could think with Taylor’s (1985) conception of “radical re-evaluation” (p. 40), which he understands as a mode of evaluating that calls undefined or inexplicit values into question. Radical re-evaluation is a responsibility, a practice and a privilege that the diagnostic category of dementia works to exempt individuals from. According to the logic of interpretation for persons with dementia, any radical re-evaluation is best understood as a demonstration of a loss of self, and the existence of cognitive decline – a change in personality. The very condition of dementia, represented as vulnerability, a space of disorientation, confusion concerning where and when and how and perhaps even who one is, could be the *prima facie* condition of becoming otherwise.

### **Destabilizing Sovereignty**

Questions of personhood cannot be divorced from what Turner refers to as the “problem of the body” (1984, p. 81): i.e., its possession. Who owns the body? Or put otherwise, who has legitimate power and authority over the body? This question animates much of the current discourse on biopolitics, and is particularly salient in issues concerning the value and/or dangers of psy-interventions and professional medical expertise currently espoused by global mental health regimes. Personhood provides a pragmatic, rational and ready-made solution to the problem of the body; which is to say, that person’s own their own bodies. Understanding personhood in this way is both unsatisfactory and problematic once personhood is situated within

broader historical, cultural and socio-political contexts. For as Turner reminds us, legal definitions of persons recognize collective entities such as cities and trading corporations as persons universalis, “One person composed of many” (1984, p. 79). Turner recalls political conceptions of sovereigns as having two bodies, “One real and corruptible, one fictive and immortal” (p. 79). This, he says, makes sense sociologically given recognition of the body as both material thing and sign.

Mbembe opens his essay “Necropolitics” with the assertion that, “To exercise sovereignty is to exercise control over mortality and to define life as the deployment and manifestation of power” (2003, p.12). Mbembe also notes that while “modernity was at the origin of multiple concepts of sovereignty” (p. 13), the concept of reason is vital to normative theories of democracy privileged by late-modern political criticism. Referring to Hegel’s articulation of a relationship between death and the “becoming subject”, Mbembe asserts that “the human being truly becomes a subject – that is, separated from the animal – in the struggle and the work through which he or she confronts death.” The truly human life (and history) is “that life which assumes death and lives with it” (Mbembe, 2003, p. 14).

How do we live with versions of life that challenge normative assumptions about death and with them, privileged conceptions of sovereignty that associate reason with freedom? Situated in relation with dementia, the becoming subject is discursively and materially produced as the shadowy figure of what Mbembe refers to as the “death-in-life” (2003, p. 21). Mbembe also draws our attention to Bataille’s conception of sacrifice not simply as a manifestation of freedom – an expression of personhood – but comedy, what Bataille refers to as “voluntary self-trickery” (p. 336, as cited in Mbembe, 2003). Guided by Mbembe and Bataille, we may now return to the narrative of the tub and the plug, and question how expert and anecdotal understandings of the inescapable tragedy of dementia (death-in-life), and institutionalization as the final frontier of human relationality (a room with a widow), restrict the performance of the self as the property of an individual fully aware of his or her death, and thus fully a person. In questioning the normative grounds of privileged understandings of dementia, assertions of a claim to the status of being “full subjects capable of self-understanding, self-consciousness and self-representation” (Mbembe, 2003, p. 13) become present in the form of semi-scripted rehearsals that carve out space within which non-disability can symbolically enact the death of disability, it’s a significant other.

Mbembe examines sacrifice through the body of the suicide bomber, which he describes as “the spectacular putting to death of the self” (2003, p. 38). The sacrifice in the story of the dementia caregiver manifests in the symbolic death of dementia as a central artery in an intersubjective and intercorporeal becoming otherwise. With-dementia the humanity of the becoming subject is constructed as a thing that can be recovered and preserved through demonstrations of yet unarticulated, but no less expected, normative values. Humanity appears in

negative form – as a thing that is liquid and slippery (Burke, 2014b); a form of capital that can slide over edges and through cracks, off the sides of spoons. Humanity, as the product and project of modernity, is a temporal thing, an occasion, to rediscover the power of practical reason to liberate individuals from their cultural containers, whether they be institutionalized settings, patriarchal economies or ageist assumptions, to devise better, more timely (i.e., culturally relevant) ways of understanding these containers; a thing, the true knowledge of which, can be used to separate and reify relations of care into events that both give life and are draining.

In framing resistance to diagnostic evaluation in humanistic terms, as an expression of individuality, and living proof of the perseverance of the self, the daughter laboured to communicate her understanding of her mother as retaining a claim to “human” life, and as being a person who is aware of the situation she is in and who can respond with reason. While the aging woman with dementia, the mother, was one protagonist in this story, she didn’t speak, and truth be told she wasn’t there for the telling. And while the story told was moving in its evocation of an important part of who she is, or at least how her family perceives her to be, a playful and agentive, very funny lady; its telling also legitimized the authority a singular and very narrow notion of sovereignty; one that, coincidentally, had also conditioned the possibility of searching the Internet for answers to the problem she is perceived to be becoming, and of routinely speaking of her life, thoughts, experiences and aspirations as though she wasn’t there. The power of the punch line relies on an affirmation of normative conceptions of awareness, of “insight” into death, as a question of knowing when to say to pull the plug.

This particular exchange illustrates a fundamental limitation to reclamation narratives told by people who may live with dementia, but who are as yet, still on the periphery of becoming recognizable as suffering from a loss of self. The same Western rationality that locates the self in the mind is also a condition of its dislocation, the dissolution of the mind and dispossession of the body. What is ontologically disruptive (and productive) about the bodily being of cognitive impairment within the context of dementia, and particularly, dementia understood as a condition of abnormal aging, concerns a destabilization of previously accepted and normatively assumed frames of reference. Without romanticizing this destabilization, as Mbembe (2003) suggests political criticism has done of sovereignty, and working to be present to the variegated nature of lived experiences of it, there is an undeniable generative power to the introduction of profound, and is often the case with dementia, unexpected, changes in language and communication.

### **Conclusion – From Personhood to Posthuman**

We conclude our analysis by turning to Braidotti’s (2013) conception of the “posthuman”, which she understands as an off-shoot of the death or “de-centering of Man, the former measure of all things” (p. 3)<sup>2</sup>. According to Braidotti, “The posthuman condition introduces a qualitative shift in our thinking about what exactly is the basic unit of common reference for our species,

our polity and our relationship to the other inhabitants of this planet” (2013, pp. 2-3). She also says, “I believe that the posthuman condition can facilitate the task of defining a new role for Europe in an age where global capitalism is both triumphant and clearly deficient in terms of sustainability and social justice” (2013, pp. 52-53). There is something problematic about Braidotti’s conceptualization of the significance of posthuman condition as a tool for redefining Europe and which focuses on cartographies for different subject positions. In defining a new role for Europe, as well as for the daughter caregiving for her mother with dementia, are we moving to the next meditation? Is this just about recognizing that we think and exist but are also finite and limited? Is the posthuman condition more authentic than humanism for its recognition of the other’s resistance, with the qualitative distinction that this other is recognized as a significant other, a co-resident? Braidotti’s rather functionalist conception of posthumanism in her reference to its role of facilitator in “the task of redefining a new role for Europe” reproduces the Eurocentric commitment to a universal consciousness, its practice of beginning the search for the truth of the structure of that consciousness by attending to a localized deficiency, and a belief in Europe’s responsibility to care for the world.

To borrow from Rose and Abi-Rached (2013), one might say this conception of the posthuman represents, rather, a “new register or dimension of selfhood, alongside older ones.” With the exception that here we can “understand and take care of ourselves” by “discerning” (Titchkosky, 2014, p. 125), as well as mapping and acting on “transversal connections” (Braidotti, 2013, p. 93), those invisible connections between subject positions beyond the centre. As crucial as such a move may seem to the vitality of relationalities and the possibilities of recomposition through affirmative bonds, the basic tenets of Western reason and politics persist, albeit in the form of the yet unarticulated correct choice; correct to the extent that it displays rational insight regarding matters of significance to the current historical moment (what can be done). As in the narrative of the tub that must be emptied, communicating a sense of the becoming subject involves a thought experiment that plays with the death of the significant other – the Human – as a means of coming to terms with the true nature of the process of becoming, now figured in terms of an assemblage of relations that can and should be mapped. Perhaps the time has come for a genealogy of history that de-centres the dominant conception of sovereignty Mbembe discusses, and that re-centres the current fascination with the subject within the political paradox of normal aging.

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### Endnotes

<sup>1</sup> For an artful analysis of narratives of Alzheimer's Disease which makes use of Ricoeur's concept of oneself as another please see: Burke, L. (2014a). Oneself as another: Intersubjectivity and ethics in Alzheimer's illness narratives. *Narrative Works*, 4, 28-47.

<sup>2</sup> See also Erevelles' "Materializing Normalcy at the Intersections of Difference: Theoretical Impasses" presented at the *Theorising Normalcy and the Mundane* conference in 2014 at University of Sheffield.

## Notes from the Field

James Sheldon, Kai Rands, Rachel Lambert, Paulo Tan, Elizabeth De Freitas, Nathalie Sinclair, Katherine E. Lewis, and Jeremy Stratton-Smith are pleased to announce a working group titled “Reframing Interventions in Mathematics Education: Critical Perspectives” to be held at the Psychology of Mathematics-Education 38<sup>th</sup> conference from Nov 3-6 in Tucson Arizona. For more information, please visit: <http://wp.me/P303g1-2d>

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