

Aging With Disability: Populations, Programs, and the New Paradigm An Introduction to the Special Issue

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Ivan R. Molton, PhD¹ and Anne Ordway, PhD¹

Abstract

Objective: The purpose of this article is to introduce a special issue dedicated to research at the intersection of aging and disability. **Method:** We provide some context for the importance of cross-disciplinary collaboration among aging and disability researchers and summarize the nine articles in this issue.

Results: Articles in the special issue are centered around several overarching themes. These include meaningful social and community participation, goals and values in the context of disability, and the reach and effectiveness of programs and policies on rehabilitation and service utilization. **Conclusion:** As care models continue to merge aging and disability services, collaboration among traditional aging and disability research networks can lead to improved outcomes for adults aging with long-term disability.

Keywords

aging and disability, long-term disability, rehabilitation

In the United States and elsewhere, a significant demographic shift is taking place among people living with early-acquired disability. The average age of people living with disability-associated conditions such as cerebral palsy,

¹University of Washington, Seattle, USA

Corresponding Author:

Ivan R. Molton, Department of Rehabilitation Medicine, University of Washington, 1959 NE Pacific St, Seattle, WA 98195, USA.

Email: imolton@uw.edu

spinal cord injury (SCI), and multiple sclerosis (MS) is steadily increasing. In North America and Europe, approximately half of individuals with MS are now 50 years or older (Foulon et al., 2018; Marrie, Yu, Blanchard, Leung, & Elliott, 2010) and more than a third of adults with SCI are older than 60 years (Halvorsen et al., 2019; Farry & Baxter, 2010). This change in demography reflects both general population aging and, for certain conditions, medical advances promoting early survivorship and disease control (Leray, Moreau, Fromont, & Edan, 2016; Minden, Marder, Harrold, & Dor, 1993; Strauss, Devivo, Paculdo, & Shavelle, 2006). These individuals are often said to be aging “with” disability (Verbrugge, Latham, & Clarke, 2017) and include those with lifelong impairments and restrictions (i.e., disability from birth or early childhood) as well as those with onset of disability before middle age (Putnam, 2017). Although precise estimates of this heterogeneous population are not available, between 12 and 14 million adults may be aging with disability in the United States (LaPlante, 2014).

One consequence of this new demographic reality is a greater degree of contact and overlap among disability and aging research networks. Perhaps not surprisingly, this new closeness has led to some growing pains and misunderstandings (Coyle & Mutchler, 2017; Nalder et al., 2017; Putnam, 2014). These two groups have traditionally been siloed by separate research and service networks that see disability through different lenses. Fundamentally, differences in focus among aging and disability research networks tend to be about onset and trajectory of ability across the lifespan. Significant disability comes after retirement for most able-bodied adults (Wolf, Freedman, Ondrich, Seplaki, & Spillman, 2015) but generally before middle-age for those with early-onset neurologic or musculoskeletal conditions. As a result, lines defining research in aging and disability have historically been drawn based on *when* in life disability first emerges.

The challenge with this kind of parcellation is that timing of disability onset is confounded by condition or diagnosis, as certain conditions appear sooner than others. Thus, one unintended consequence of this unofficial delineation appears to be the creation of unspoken lists of conditions that “belong” to each research network. For example, aging researchers study caregiving in Alzheimer’s disease (Ashida, Marcum, & Koehly, 2018; Wang et al., 2018), whereas disability researchers study caregiving in SCI (Kang et al., 2018; Smith, Boucher, Miller, & Team, 2016). The research on self-efficacy and MS is mostly held in rehabilitation and neurology journals (Calandri, Graziano, Borghi, & Bonino, 2019; Casey et al., 2018; Kalina et al., 2018), but the research on self-efficacy and osteoarthritis is mostly held in aging and rheumatology journals (Jackson, Xu, & Jia, 2019; Rejeski, Miller, Foy, Messier, & Rapp, 2001). There are conditions at the intersection

of aging and disability research, such as Parkinson's disease and transdiagnostic symptoms or problems (e.g., pain, fatigue, and fall risk). However, in general, territories are marked not by commonalities of service needs, ability, or disability but by an undeclared list of medical conditions based on typical age of onset. One can see the shadow of this list reflected in funding priorities and initiatives of federal and private aging and disability research organizations, which directly influence the research agendas of these fields.

This traditional delineation of research fields by diagnoses and timing of onset limits the productivity of research for both fields and is a luxury neither can afford. With population aging, one in five new SCIs occurs in adults above 50 years of age (National Spinal Cord Injury Statistical Center, 2018). Cardiac disease remains a disabling condition in both older adults and in younger people with neuromuscular dystrophies (Feingold et al., 2017). As individuals with Down syndrome age into risk for Alzheimer's disease (Carmona-Iragui, Videla, Lleo, & Fortea, 2019; Rafii & Santoro, 2019) or those with cerebral palsy age into new limitations due to osteoarthritis and osteoporosis (Cremer, Hurvitz, & Peterson, 2017; Whitney et al., 2018), there is a significant potential for shared knowledge and collaboration among these research communities. Both older adults and those with disabilities face stigma and stereotyping (National Academies of Sciences Engineering and Medicine, 2018), require integrated rehabilitative services, need long-term services and supports for community participation (Putnam, 2014, 2017), and benefit from accessible community health promotion programs (Behm et al., 2016; Gainforth, Latimer-Cheung, Athanasopoulos, Martin, & Ginis, 2015; Newman et al., 2014). Those aging with disability and those aging into disability have too much in common to be served by divided research silos.

Where are the barriers? In terms of bridging aging and disability service networks, a number of specific challenges have been identified, including problems with categorical service systems based on age or disability type (Bickenbach et al., 2012; Campbell & Putnam, 2017; Nalder et al., 2017; Putnam, 2014, 2017). Related barriers in research networks include limited assessment of time of onset and duration of disability in U.S. public-use secondary data sets (Putnam, Molton, Truitt, Smith, & Jensen, 2016), differences in language and conceptualization of disability, and lack of cross-disciplinary citation in scientific publications. Both literature also suffer from a lack of inclusion—of both people with long-term disability (LTD) in aging studies and of older adults in studies of people with LTD.

Differences in language among aging and rehabilitation disciplines are common and have been described elsewhere (Coyle & Mutchler, 2017). For example, disability researchers often talk about symptoms such as pain or fatigue as “secondary conditions” (Pilusa, Myezwa, & Potterton, 2019), a

term of little meaning or utility to geriatricians. There is a tendency of researchers to describe “caregivers” or “caregiver support” (Rote & Moon, 2018; Roth, Brown, Rhodes, & Haley, 2018) in the aging literature and “care partners” (Eilers, 2013) or “family support” (Heller, Gibbons, & Fisher, 2015) in the disability literature. These kinds of language differences are relatively minor but contribute to problems in cross-network communication.

At a much larger level, however, aging and disability researchers may differ in their conceptualization of disability. In 2001, the World Health Organization (WHO) published their International Classification of Functioning, Disability and Health (the ICF model) in part to establish a consistent conceptualization of disability for use across disciplines and settings (WHO, 2001). This model emphasizes a biopsychosocial approach in which disability represents activity limitations and participation restrictions resulting from the interaction of a health condition and contextual factors. Generally speaking, gerontologists and rehabilitation researchers are trained and well-versed in this model.

However, the ICF is a very broad framework, and as a result, various sub-disciplines may focus almost exclusively on particular components of the model as foundational to their conception of disability. For example, rehabilitation researchers tend to come from medical backgrounds and may emphasize physical aspects of disability. At times, this has led to the unfortunate shorthand of medical rehabilitation researchers to conflate a particular health condition with disability (e.g., “disabilities such as SCI” [Etingen et al., 2018; Molton, Jensen, Nielson, Cardenas, & Ehde, 2008; Nightingale et al., 2018] or “disabilities such as MS” [Pack, Szirony, Kushner, & Bellaw, 2014]). This kind of inadvertent medicalization is anathema to those in disability studies, who tend to emphasize disability primarily as a social construction (Logan, Bogart, Ross, & Woekel, 2018) regardless of the cause or nature of impairment. A parallel exists in the field of aging. Medical geriatricians and those studying antiaging strategies may see aging-related disability as a thing to be prevented, ameliorated, or cured (Hou et al., 2018; Manayi, Saeidnia, Gohari, & Abdollahi, 2014) and, thereby, talk about disability in terms of loss or decline. Social gerontologists, on the contrary, are more likely to describe disability in terms of social and cultural barriers to access and participation (Tinker, Hussain, D’Cruz, Tai, & Zaidman, 2016) and emphasize the need for supports. Policy and health services researchers in both fields are often limited by what is available in health care claims data and national surveys and may define disability in terms of types that merge impairments and restrictions (e.g., hearing, vision, cognition, and mobility [Okoro, Hollis, Cyrus, & Griffin-Blake, 2018]) or a combination of proxies of disability (e.g.,

self-reported restrictions and use of adaptive equipment [Fan, Strine, Jiles, Berry, & Mokdad, 2009]).

Taken together and in the broadest possible terms, researchers in aging may think of disability in terms of problems *doing*, a result of the interaction of impairment and one's environment. Disability researchers tend to think of disability in terms of an identity (Andrews et al., 2019; Forber-Pratt & Zape, 2017) that is sometimes tied to the culture around a specific diagnosis or label (Chapman & Dammeyer, 2017; Kapp, Gillespie-Lynch, Sherman, & Hutman, 2013) and viewed in the context of a long movement for disability rights (Forber-Pratt, Mueller, & Andrews, 2019; Forber-Pratt & Zape, 2017). There is room for all these perspectives within the biopsychosocial ICF framework, and restricting the conversation to only one aspect or definition of disability would not be fruitful. However, it is worth acknowledging that when aging and disability researchers (including their respective subdisciplines) talk about disability, there is no guarantee that they are referring to the same phenomenon.

Another barrier to bridging comes in a lack of scientific interaction between disciplines. Simply put, it is not clear that researchers in aging and disability fields are reading one another's work. In 2013, our group attempted to analyze the degree to which disability/rehabilitation researchers and geriatrics/gerontology researchers were citing one another's publications in key peer-reviewed journals (Molton & West, 2013). We first identified 97 journals in the Thompson Reuters Journal Citation Reports Database relevant to the fields of geriatrics, gerontology, disability studies, rehabilitation sciences, and medical rehabilitation. Then, using a series of bibliographic techniques based in network analysis (Rosvall & Bergstrom, 2010, 2011), we identified clusters of these journals based on citation patterns and determined the extent to which these clusters cited one another over time. Results were quite striking—less than 20% of the flow of citations went between aging and disability journal clusters, and cross-citation between those clusters occurred in only a handful of intermediary journals. This pattern did not change significantly in any year from 1997 to 2010. The analysis also suggested that articles in the geriatrics/gerontology cluster were almost twice as likely to cite those in the disability/rehabilitation cluster than the reverse. Although preliminary (disseminated as a conference presentation and, therefore, not peer reviewed), these data provided some quantitative support to long-standing observations of aging and disability research silos and also suggested that researchers in disability and rehabilitation were not well informed of the aging literature.

This lack of scientific dialogue and resulting disconnection is readily apparent in several key areas of the aging and disability literature. Perhaps, the clearest example is in the concept of “successful aging.” Despite robust and

vigorous debate in aging research about what constitutes successful aging (Rowe & Kahn, 2015), it remains true that most models of successful aging focus on the physiologic process of aging, such as physical function (Rowe & Kahn, 1997), longevity (Perls, Silver, & Lauerman, 1999), and physical activity (Antikainen et al., 2010), as well as the absence of chronic disease and disability (Bowling, 2007; Depp & Jeste, 2006; Phelan & Larson, 2002; Rowe & Kahn, 1987). The criteria of “freedom from disability” or “high/independent functioning” are historically widespread in published definitions (reviewed in Phelan & Larson, 2002) and are present in as many as 90% of empirical studies on the topic (Depp & Jeste, 2006).

From the perspective of those in the aging field, the prevention or delay of disability is an important goal that has significant social and economic implications (Olshansky, Perry, Miller, & Butler, 2007). To those in the disability field, however, a requirement for the absence of chronic illness or disability as an indicator of successful aging is deeply problematic and even oppressive (Molton & Yorkston, 2017) because in the strictest sense, individuals aging with early-acquired disability could not age successfully. In defining successful aging as the absence of disability, individuals with disability have been overtly and specifically excluded from foundational studies on this model (Bruce, Seeman, Merrill, & Blazer, 1994). Such criteria do not account for the wide range of accommodations and adaptations that individuals with disability may make to preserve autonomy as they age. This may explain the lack of attention the successful aging concept has received in disability research and why only a handful of studies in the fields of disability or rehabilitation have investigated this phenomenon (Jorgensen, Iwarsson, & Lexell, 2017; LaPlante, 2014; Molton & Yorkston, 2017; Ploughman et al., 2012).

A more pragmatic example of this disconnect is seen in the scientific literature that forms the evidence base for community programming for older adults. States that receive Older Americans Act Title III-D funds must use those funds for health programming to reduce disease and improve health in community living older adults. Since 2012, these programs are required to be evidence-based, meaning that they must meet certain established criteria including demonstrated effectiveness in an older adult population and publication in a peer-reviewed journal. While these evidence-based programs (EBPs) were mostly developed to serve community-living older adults, they are increasingly used to serve adults aging with long-term or early-acquired disabilities. Yet, for whom are these programs evidence-based? It is not clear that people with early-onset disabilities have been included in research trials of these Title III-D qualifying EBPs. In fact, in a number of cases, there is evidence of direct or indirect exclusion of people with disabilities in this literature. Only rarely is this exclusion overt—for example, in studies that have

excluded participants based on “a history of . . . musculoskeletal, and/or neurologic limitations that could account for possible imbalance and falls such as . . . spinal cord injury” (Beling & Roller, 2009, p. 125) or on being “fully work-disabled” (Detaille, Heerkens, Engels, van der Gulden, & van Dijk, 2013, p. 192). In other cases, exclusion occurred indirectly through criteria that prevented participation from people who required assistance from a care partner, such as those who “were not able to walk without support from another person” (Kyrdalen, Moen, Roysland, & Helbostad, 2014, p. 109) or those who were “unable to transfer unassisted from a wheelchair” (Callahan et al., 2014, p. 286). Individuals with disability have also been excluded through subjective and vague exclusion criteria regarding health, such as those who were “free of medical conditions or disabilities that required higher levels of supervision, as determined by lead staff” (Baruth & Wilcox, 2011, p. 1039) or those with “advanced neurological disorder,” because the group-based self-management program being studied “was considered inappropriate for these potential participants” (Swerissen et al., 2006, p. 362). Finally, participants with early-onset disability may have been indirectly excluded from randomized controlled trials (RCTs) based on a lack of adapted outcomes. Especially, in trials of disease management and fall prevention interventions, outcomes may include objective measures of fitness, such as the 6-min walk test (Cameron-Tucker, Wood-Baker, Owen, Joseph, & Walters, 2014) or the timed up-and-go test (TUG; Cho et al., 2012). Even if participants who are primary wheelchair users are included in the intervention trial, without thoughtful selection and adaption of outcome measures, they could not contribute to outcomes data. For example, if a primary outcome is gait speed as defined by the TUG, then participants who cannot perform the TUG are necessarily dropped from efficacy testing (Cho et al., 2012).

This does not mean that people with early-acquired or LTD do not or cannot participate in falls prevention, disease self-management, exercise, or other EBPs supported by Title III-D funds. Unquestionably, they do and can and to good benefit (as described in two studies in this issue). Yet, there are fewer than three studies that *specifically* describe including people with early-onset disabilities in interventions supported by Title III-D funds (see, for example, the qualitative report of Chronic Disease Self-Management Program [CDSMP] in people with MS and SCI; Hirsche, Williams, Jones, & Manns, 2011). This absence is especially telling as it has been hypothesized that some EBPs may be even more effective for those with higher levels of disability or poorer self-reported health at baseline (Cho et al., 2012). It also should be noted that this problem of inclusion/exclusion cuts both ways. There are certainly examples within the disability literature of studies that define “adult” as 18 to 65 years of age and, thereby, exclude older

participants from adapted physical activity interventions (for example, Young, Mehta, Herman, Wang, & Rimmer, 2019).

Despite these challenges, the fields of aging and disability research seem to be moving toward a new paradigm of increased cooperation and dialogue. A number of recent approaches and attempts at bridging these fields have resulted in meetings, publications, and knowledge translation products that directly speak to the intersection of aging and disability research (Coyle & Mutchler, 2017; Nalder et al., 2017). These changes in research reflect a larger shift to merge aging and disability service organizations at both the state and federal levels. Perhaps, the clearest example of a significant bridge between the aging and disability fields is in the Administration for Community Living (ACL), which now includes the Administration on Aging, the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), and the Administration on Disabilities. In fact, a number of the studies in this special issue were funded by a NIDILRR Rehabilitation Research and Training Center focused on aging and disability (2013-2018), and this center now continues in its ninth cycle (2018-2023). A future of greater cooperation and increased understanding among aging and disability researchers can make substantial contributions to improving the lives of those aging with and into disability.

Contents of the Special Issue

The purpose of this special issue is to highlight a selection of areas in which aging and disability research is merging and to present some innovative work at this intersection. Mirroring the diversity of views on aging and disability in the larger literature, articles in this special issue approach the intersection of these two fields differently. Some describe the effects of age in populations of people with long-term conditions and impairments. Others seek to define LTD using large secondary data sets or to describe new onset of traumatic disability in former able-bodied older adults. Reflecting the breadth and depth of this new field, topics range from measurement development to the impact of Medicaid managed care (MMC) to effects of state-level legislation affecting caregiver training.

Although diverse, these nine articles can be organized around four themes describing issues that are salient to people with disabilities as they age: (a) expanding the reach and effectiveness of evidence-based health promotion and disease prevention programs for people aging with disability, (b) evaluating policies and programs focused on the utilization of rehabilitation and other services and supports, (c) improving opportunities for meaningful social and community participation, and (d) living a life consistent with

personal values and goals in the context of disability. These research studies also illuminate the experiences of different subpopulations of people aging with disability including people with physical, intellectual/developmental, and neurocognitive disabilities.

Expanding the Reach and Effectiveness of EBPs

Over the past 15 years, there has been a focus on developing and implementing evidence-based health promotion and disease prevention programs for older adults at high risk of developing chronic or secondary health conditions. Only recently have researchers started examining the reach and effectiveness of these programs for people aging with disability. Ferretti and McCallion examined the feasibility of adapting the CDSMP for older adults with developmental disabilities. The findings of this study support the use of supplementary materials and caregiver or staff assistance in the successful delivery of the CDSMP to this population. The authors concluded that making self-management programs more accessible to older adults with developmental disabilities especially in mainstream versus segregated settings has the potential to improve their general health and quality of life.

Eagen and colleagues compared the reach and effectiveness of two evidence-based falls prevention programs between older adults with and without disability-associated conditions that typically onset before 40 years of age. These participants were described as having LTD. Using a matched case-control design, older adults with disability enrolled in A Matter of Balance (MOB) or Stepping On were matched to older adults without LTD. The authors found that older adults with LTD attended a higher number of class sessions and were significantly more likely to complete the falls prevention programs. They also found that older adults with LTD were equally likely as older adults without LTD to report significant reductions in self-reported fear of falling, falls-related activity restriction, and improvement in falls self-efficacy. These findings provide preliminary evidence for the effectiveness of these evidence-based falls prevention programs for older adults with LTD.

Evaluating Policies and Programs Focused on the Utilization of Rehabilitation and Other Services and Supports

There has been a growing trend to align policies and programs focused on improving health care services and long-term services and supports for people with disabilities and older adults. Hammond and colleagues investigated the

functional outcomes at 1-year postinjury in a sample of older adults with new traumatic brain injury (TBI) who received inpatient rehabilitation services. The authors found a variety of factors associated with 1-year TBI outcomes among older adults. For example, older age was associated with milder injuries but less improvement in functional outcomes despite similar lengths of acute care and rehabilitation hospital stays across all age groups. They also found that functional outcomes at discharge from inpatient rehabilitation stays were the strongest contributor to better global functioning across all age groups. These findings have important implications for the care needs of older adults with TBI, which may include longer and more intensive inpatient rehabilitation services to maximize the potential for long-term recovery. The authors concluded that additional research into age-specific predictors of functional outcomes is warranted to inform the development of targeted interventions to optimize TBI recovery in older populations.

The share of Medicaid spending that goes to managed care has increased in most states. In an effort to control state expenditures and to provide better access to health services for enrollees, states have been transitioning Medicaid enrollees with disabilities from the fee-for-service (FFS) model to the MMC model. In the next study in this special issue, Yamaki and colleagues evaluated the impact of MMC on hospital-based service use and its state costs in a sample of adults with early-acquired physical disabilities. Using MMC claims data, the authors tracked utilization of the emergency department (ED) visits, inpatient admissions, outpatient primary care physician visits, and state health services expenditures on enrollees who transitioned to MMC. The authors found that MMC reduced ED use, inpatient admissions, and state expenditures for older enrollees (age 46 years and older). The authors concluded that MMC could reduce the hospital service use of and state spending on older enrollees with early-acquired physical disabilities.

There has been considerable momentum to establish national training standards for the long-term care workforce—particularly direct care workers. Ordway and colleagues investigated the impact of Washington State Initiative 1163, the first state mandate that all long-term care workers providing personal care services in a community-based setting complete a standardized training curriculum and skills test to be certified as a home care aide (HCA). The authors used exploratory research to understand the perceived impact of the upgraded training and certification requirements on personal care services from the perspectives of consumers (recipients of care) and HCAs. Themes emerged on the perceived value of a standardized, competency-based HCA training program compared with a customized, consumer-provided training. Preliminary findings also pointed to the value of defining at a more granular level the knowledge, skills, and attitudes expected of HCAs providing home-based personal care services. State-based efforts, such as

this one in Washington State, serve as an important starting point for building a broader effort toward the identification of competencies and associated training standards for direct care workers nationally.

Improving Opportunities for Meaningful Social and Community Participation

The discourses on disability and aging promote the benefits of participation in social and community activities to an individual's general health and quality of life. Clarke and colleagues examined the association between individual (e.g., demographic characteristics) and socio-environmental factors (e.g., perceived social support and inaccessible sidewalks, paths, and streets) and social role participation in a sample of individuals aging with long-term conditions associated with disability. Findings from this study indicated a positive indirect relationship between age and social role participation. The authors also found that facilitators to social role participation were perceived social support, whereas barriers to social role participation were an inaccessible built environment. The findings from this study highlight the importance of both individual and socio-environmental factors for social role participation among people aging with early-onset physical disabilities.

Similarly, Dashner and colleagues examined differences in several dimensions of community participation (e.g., frequency of site visits, satisfaction with participation, and use of assistive devices) for individuals with disabilities of two different age cohorts (below and above 50 years of age) as well as for individuals with early- and late-onset disability (onset prior to and after 40 years of age). Community participation was assessed by the frequency of site visits at specific locations in an individual's community. The findings from this study indicated some significant differences in community participation based on age but not on onset of disability. For example, individuals aged 50 years and older visited more frequently sites that were focused on health (e.g., pharmacies), whereas individuals below 50 years of age visited more frequently sites that were focused on leisure (e.g., restaurants, movie theaters, and shopping malls). The results of this study provide a unique view of community participation for people aging with disability.

Approaches to Personal Values and Goals in the Context of Disability

Maintaining personally meaningful values and goals in the context of changes in an individual's disease-specific symptoms and functional status is an important component of successful aging for people with disabilities. Jensen and

colleagues examined the reliability and validity of the Valued Living Scale (VLS)—a measure to assess goal importance, success, and confidence with respect to eight global value domains—in a sample of individuals aging with SCI, MS, post-polio syndrome (PPS), or muscular dystrophy. Findings from this study indicated that the VLS items assessed two valued living subdomains: a social and relational subdomain and a health and productivity subdomain. This study provides preliminary evidence to support the VLS as a reliable and valid measure of successful aging in individuals aging with early-acquired disability.

In the final study for the special issue, Arewasikporn and colleagues have applied the Brandtstädter's (2009) dual-process framework to a sample of middle-aged people with conditions associated with LTD. Specifically, they examined whether tenacious goal pursuit (TGP) and flexible goal adjustment (FGA) were associated with a decreased symptom burden and whether TGP and FGA protected against the impact of pain intensity in a sample of individuals aging with SCI, MS, PPS, and neuromuscular disease. Findings from this study indicated that higher TGP and FGA at baseline were differentially associated with positive outcomes 1 year later. These two styles may also work in tandem, as high TGP was associated with decreases in pain interference when FGA was also high. However, neither TGP nor FGA buffered the associations between pain intensity and other symptoms associated with long-term physical disability. The findings from this study support previous research that individuals with early-onset physical disabilities may benefit from coaching in a combination of these goal management strategies and that these goal management strategies may improve symptom management.

Conclusion

Despite more than a century of parallel research, in many ways, the intersection of aging and disability research networks remains in its infancy. Differences in language and conceptualization of disability remain and can limit shared opportunities. In a case of research following policy change, the merger of services for older adults and people with disabilities has created the urgent need for greater communication to answer questions about how best to support an aging minority population (Campbell & Putnam, 2017). This special issue seeks to contribute to this effort and to continue the conversation among aging and disability research networks.

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References

- Andrews, E. E., Forber-Pratt, A. J., Mona, L. R., Lund, E. M., Pilarski, C. R., & Balter, R. (2019). Say the word: A disability culture commentary on the erasure of "disability." *Rehabilitation Psychology, 64*, 111-118. doi:10.1037/rep0000258
- Antikainen, I., Ellis, R., Kosma, M., Allen, P. D., Cherry, K. E., Monroe, P. A., & Wood, R. H. (2010). Examining change in theory-based physical activity beliefs of culturally diverse older adults. *Journal of Applied Gerontology, 29*, 507-517. doi:10.1177/0733464809341469
- Ashida, S., Marcum, C. S., & Koehly, L. M. (2018). Unmet expectations in Alzheimer's family caregiving: Interactional characteristics associated with perceived under-contribution. *Gerontologist, 58*, e46-e55. doi:10.1093/geront/gnx141
- Baruth, M., & Wilcox, S. (2011). Effectiveness of two evidence-based programs in participants with arthritis: Findings from the Active for Life Initiative. *Arthritis Care & Research, 63*, 1038-1047. doi:10.1002/acr.20463
- Behm, L., Eklund, K., Wilhelmson, K., Ziden, L., Gustafsson, S., Falk, K., & Dahlin-Ivanoff, S. (2016). Health promotion can postpone frailty: Results from the RCT Elderly Persons in the Risk Zone. *Public Health Nursing, 33*, 303-315. doi:10.1111/phn.12240
- Beling, J., & Roller, M. (2009). Multifactorial intervention with balance training as a core component among fall-prone older adults. *Journal of Geriatric Physical Therapy, 32*, 125-133. doi:10.1519/00139143-200932030-00008
- Bickenbach, J., Bigby, C., Salvador-Carulla, L., Heller, T., Leonardi, M., LeRoy, B., . . . Spindel, A. (2012). The Toronto declaration on bridging knowledge, policy and practice in aging and disability. *International Journal of Integrated Care, 12*, Article e205.
- Bowling, A. (2007). Aspirations for older age in the 21st century: What is successful aging? *The International Journal of Aging & Human Development, 64*, 263-297. doi:10.2190/10k1-87w4-9r01-7127
- Brandtstadter, J. (2009). Goal pursuit and goal adjustment: Self-regulation and intentional self-development in changing developmental contexts. *Advances in Life Course Research, 14*, 52-62. doi:10.1016/j.alcr.2009.03.002
- Bruce, M. L., Seeman, T. E., Merrill, S. S., & Blazer, D. G. (1994). The impact of depressive symptomatology on physical disability: MacArthur Studies of Successful Aging. *American Journal of Public Health, 84*, 1796-1799.

- Calandri, E., Graziano, F., Borghi, M., & Bonino, S. (2019). Young adults' adjustment to a recent diagnosis of multiple sclerosis: The role of identity satisfaction and self-efficacy. *Disability and Health Journal, 12*, 72-78. doi:10.1016/j.dhjo.2018.07.008
- Callahan, L. F., Cleveland, R. J., Shreffler, J., Hootman, J. M., Mielenz, T. J., & Schoster, B. (2014). Evaluation of active living every day in adults with arthritis. *Journal of Physical Activity & Health, 11*, 285-295. doi:10.1123/jpah.2011-0317
- Cameron-Tucker, H. L., Wood-Baker, R., Owen, C., Joseph, L., & Walters, E. H. (2014). Chronic disease self-management and exercise in COPD as pulmonary rehabilitation: A randomized controlled trial. *International Journal of Chronic Obstructive Pulmonary Disease, 9*, 513-523. doi:10.2147/Copd.S58478
- Campbell, M. L., & Putnam, M. (2017). Reducing the shared burden of chronic conditions among persons aging with disability and older adults in the United States through bridging aging and disability. *Healthcare, 5*(3), 56. doi:10.3390/healthcare5030056
- Carmona-Iragui, M., Videla, L., Lleo, A., & Fortea, J. (2019). Down syndrome, Alzheimer disease, and cerebral amyloid angiopathy: The complex triangle of brain amyloidosis. *Developmental Neurobiology, 79*, 716-737. doi:10.1002/dneu.22709
- Casey, B., Uszynski, M., Hayes, S., Motl, R., Gallagher, S., & Coote, S. (2018). Do multiple sclerosis symptoms moderate the relationship between self-efficacy and physical activity in people with multiple sclerosis? *Rehabilitation Psychology, 63*, 104-110. doi:10.1037/rep0000190
- Chapman, M., & Dammeyer, J. (2017). The significance of deaf identity for psychological well-being. *Journal of Deaf Studies and Deaf Education, 22*, 187-194. doi:10.1093/deafed/enw073
- Cho, J., Smith, M. L., Ahn, S., Quinn, C., Wilson, A., & Ory, M. G. (2015). Gait speed among older participants enrolled in an evidence-based fall risk reduction program: A subgroup analysis. *Frontiers in Public Health, 3*, 1-7. doi:10.3389/fpubh.2015.00026
- Coyle, C. E., & Mutchler, J. E. (2017). Aging with disability: Advancement of a cross-disciplinary research network introduction. *Research on Aging, 39*, 683-692. doi:10.1177/0164027516681895
- Cremer, N., Hurvitz, E. A., & Peterson, M. D. (2017). Multimorbidity in middle-aged adults with cerebral palsy. *American Journal of Medicine, 130*, 744.e9-744.e15. doi:10.1016/j.amjmed.2016.11.044
- Depp, C. A., & Jeste, D. V. (2006). Definitions and predictors of successful aging: A comprehensive review of larger quantitative studies. *American Journal of Geriatric Psychiatry, 14*, 6-20.
- Detaille, S. I., Heerkens, Y. F., Engels, J. A., van der Gulden, J. W. J., & van Dijk, F. J. H. (2013). Effect evaluation of a self-management program for Dutch workers with a chronic somatic disease: A randomized controlled trial. *Journal of Occupational Rehabilitation, 23*, 189-199. doi:10.1007/s10926-013-9450-0

- Eilers, D. (2013). What's in a word—Caregiver or care partner? *Nephrology Nursing Journal, 40*, 61-62.
- Etingen, B., Martinez, R. N., Vallette, M. A., Dendinger, R., Bidassie, B., Miskevics, S., . . . Weaver, F. M. (2018). Patient perceptions of environmental control units: Experiences of Veterans with spinal cord injuries and disorders receiving inpatient VA healthcare. *Disability and Rehabilitation: Assistive Technology, 13*, 325-332. doi:10.1080/17483107.2017.1312574
- Fan, A. Z., Strine, T. W., Jiles, R., Berry, J. T., & Mokdad, A. H. (2009). Psychological distress, use of rehabilitation services, and disability status among noninstitutionalized US adults aged 35 years and older, who have cardiovascular conditions, 2007. *International Journal of Public Health, 54*, 100-105. doi:10.1007/s00038-009-1313-2
- Farry, A. & Baxter, D. (2010). *The incidence and prevalence of spinal cord injury in Canada*. Rick Hansen Institute. Retrieved from <http://fecst.inesss.qc.ca/fileadmin/documents/photos/LincidenceetlaprevalencedestraumamedullaureauCanada.pdf>
- Feingold, B., Mahle, W. T., Auerbach, S., Clemens, P., Domenighetti, A. A., Jefferies, J. L., . . . Council, S. (2017). Management of cardiac involvement associated with neuromuscular diseases: A scientific statement from the American Heart Association. *Circulation, 136*, e200-e231. doi:10.1161/Cir.0000000000000526
- Forber-Pratt, A. J., Mueller, C. O., & Andrews, E. E. (2019). Disability identity and allyship in rehabilitation psychology: Sit, stand, sign, and show up. *Rehabilitation Psychology, 64*, 119-129. doi:10.1037/rep0000256
- Forber-Pratt, A. J., & Zape, M. P. (2017). Disability identity development model: Voices from the ADA-generation. *Disability and Health Journal, 10*, 350-355. doi:10.1016/j.dhjo.2016.12.013
- Foulon, S., Maura, G., Dalichampt, M., Alla, F., Debouverie, M., Moreau, T., & Weill, A. (2018). Prevalence and mortality of patients with multiple sclerosis in France in 2012: A study based on French health insurance data. *Journal of Neurology, 264*, 1185-1192. doi:10.1007/s00415-017-8513-0
- Gainforth, H. L., Latimer-Cheung, A. E., Athanasopoulos, P., & Martin Ginis, K. A. (2015). Examining the feasibility and effectiveness of a community-based organization implementing an event-based knowledge mobilization initiative to promote physical activity guidelines for people with spinal cord injury among support personnel. *Health Promotion Practice, 16*, 55-62. doi:10.1177/1524839914528210
- Halvorsen, A., Pettersen, A. L., Nilssen, S. M., Halle, K. K., Schaanning, E. E., & Rekand, T. (2019). Epidemiology of traumatic spinal cord injury in Norway in 2012-2016: A registry-based cross-sectional study. *Spinal Cord, 57*, 331-338. doi:10.1038/s41393-018-0225-5
- Heller, T., Gibbons, H. M., & Fisher, D. (2015). Caregiving and family support interventions: Crossing networks of aging and developmental disabilities. *Intellectual and Developmental Disabilities, 53*, 329-345. doi:10.1352/1934-9556-53.5.329
- Hirsche, R. C., Williams, B., Jones, A., & Manns, P. (2011). Chronic disease self-management for individuals with stroke, multiple sclerosis and spinal cord injury.

- Disability and Rehabilitation*, 33, 1136-1146. doi:10.3109/09638288.2010.523103
- Hou, A. Y., Chen, P., Tang, H., Meng, H. Y., Cheng, X. Q., Wang, Y., . . . Peng, J. (2018). Cellular senescence in osteoarthritis and anti-aging strategies. *Mechanisms of Ageing and Development*, 175, 83-87. doi:10.1016/j.mad.2018.08.002
- Jackson, T., Xu, T., & Jia, X. (2019). Arthritis self-efficacy beliefs and functioning among osteoarthritis and rheumatoid arthritis patients: A meta-analytic review. *Rheumatology (Oxford)*. Advance online publication. doi:10.1093/rheumatology/kez219
- Jorgensen, S., Iwarsson, S., & Lexell, J. (2017). Secondary health conditions, activity limitations, and life satisfaction in older adults with long-term spinal cord injury. *Archives of Physical Medicine and Rehabilitation*, 9, 356-366. doi:10.1016/j.pmrj.2016.09.004
- Kalina, J. T., Hinojosa, J., Strober, L., Bacon, J., Donnelly, S., & Goverover, Y. (2018). Randomized controlled trial to improve self-efficacy in people with multiple sclerosis: The Community Reintegration for Socially Isolated Patients (CRISP) Program. *American Journal of Occupational Therapy*, 72(5), 7205205030p1-7205205030p8. doi:10.5014/ajot.2018.026864.
- Kang, M. G., Kim, C. H., Park, E., Huh, J. W., Yang, W. J., Nam, T. W., . . . Jung, T. D. (2018). Effect of family caregiving on depression in the first 3 months after spinal cord injury. *Annals of Rehabilitation Medicine*, 42, 130-136. doi:10.5535/arm.2018.42.1.130
- Kapp, S. K., Gillespie-Lynch, K., Sherman, L. E., & Hutman, T. (2013). Deficit, difference, or both? Autism and neurodiversity. *Developmental Psychology*, 49, 59-71. doi:10.1037/a0028353
- Kyrдалen, I. L., Moen, K., Roysland, A. S., & Helbostad, J. L. (2014). The Otago Exercise Program performed as group training versus home training in fall-prone older people: A randomized controlled trial. *Physiotherapy Research International*, 19, 108-116. doi:10.1002/pri.1571
- LaPlante, M. P. (2014). Key goals and indicators for successful aging of adults with early-onset disability. *Disability and Health Journal*, 7, S44-S50. doi:10.1016/j.dhjo.2013.08.005
- Leray, E., Moreau, T., Fromont, A., & Edan, G. (2016). Epidemiology of multiple sclerosis. *Revue Neurologique (Paris)*, 172, 3-13. doi:10.1016/j.neurol.2015.10.006S0035-3787(15)00919-4
- Logan, S. W., Bogart, K. R., Ross, S. M., & Woekel, E. (2018). Mobility is a fundamental human right: Factors predicting attitudes toward self-directed mobility. *Disability and Health Journal*, 11, 562-567. doi:10.1016/j.dhjo.2018.06.001
- Manayi, A., Saeidnia, S., Gohari, A. R., & Abdollahi, M. (2014). Methods for the discovery of new anti-aging products—Targeted approaches. *Expert Opinion on Drug Discovery*, 9, 383-405. doi:10.1517/17460441.2014.885014
- Marrie, R. A., Yu, N., Blanchard, J., Leung, S., & Elliott, L. (2010). The rising prevalence and changing age distribution of multiple sclerosis in Manitoba. *Neurology*, 74, 465-471. doi:10.1212/WNL.0b013e3181cf6ec0

- Minden, S., Marder, W., Harrold, L., & Dor, A. (1993). *Multiple sclerosis: A statistical portrait*. Cambridge, UK: Abt Associates.
- Molton, I. R., Jensen, M. P., Nielson, W., Cardenas, D., & Ehde, D. M. (2008). A preliminary evaluation of the motivational model of pain self-management in persons with spinal cord injury-related pain. *Journal of Pain, 9*, 606-612. doi:10.1016/j.jpain.2008.01.338
- Molton, I. R., & West, J. (2013). *Are aging and disability researchers talking to one another? An examination of the publication record, 1997-2010*. Paper presented at the National Association of Rehabilitation Research and Training Centers, Alexandria, VA, April.
- Molton, I. R., & Yorkston, K. M. (2017). Growing older with a physical disability: A special application of the successful aging paradigm. *Journals of Gerontology: Series B. Psychological Sciences & Social Sciences, 72*, 290-299. doi:10.1093/geronb/gbw122
- Nalder, E. J., Putnam, M., Salvador-Carulla, L., Spindel, A., Batliwalla, Z., & Lenton, E. (2017). Bridging knowledge, policies and practices across the ageing and disability fields: A protocol for a scoping review to inform the development of a taxonomy. *BMJ Open, 7*(10), e016741
- National Academies of Sciences, Engineering, and Medicine. (2018). *Aging and disability: Beyond stereotypes to inclusion: Proceedings of a workshop*. Washington, DC: Author.
- National Spinal Cord Injury Statistical Center. (2018). *Annual statistical report for the spinal cord injury model systems*. Retrieved from <https://www.nscisc.uab.edu/public/2018%20Annual%20Report%20-%20Complete%20Public%20Version.pdf>
- Newman, S. D., Gillenwater, G., Toatley, S., Rodgers, M. D., Todd, N., Epperly, D., & Andrews, J. O. (2014). A community-based participatory research approach to the development of a peer navigator health promotion intervention for people with spinal cord injury. *Disability and Health Journal, 7*, 478-484. doi:10.1016/j.dhjo.2014.04.006
- Nightingale, T. E., Moore, P., Harman, J., Khalil, R., Gill, R. S., Castillo, T., . . . Gorgey, A. S. (2018). Body composition changes with testosterone replacement therapy following spinal cord injury and aging: A mini review. *Journal of Spinal Cord Medicine, 41*, 624-636. doi:10.1080/10790268.2017.1357917
- Okoro, C. A., Hollis, N. D., Cyrus, A. C., & Griffin-Blake, S. (2018). Prevalence of disabilities and health care access by disability status and type among adults—United States, 2016. *Morbidity and Mortality Weekly Report, 67*, 882-887. doi:10.15585/Mmwr.Mm6732a3
- Olshansky, S. J., Perry, D., Miller, R. A., & Butler, R. N. (2007). Pursuing the longevity dividend: Scientific goals for an aging world. *Annals of the New York Academy of Sciences, 1114*, 11-13.
- Pack, T. G., Szirony, G. M., Kushner, J. D., & Bellow, J. R. (2014). Quality of life and employment in persons with multiple sclerosis. *Work: A Journal of Prevention Assessment & Rehabilitation, 49*, 281-287. doi:10.3233/Wor-131711

- Perls, T., Silver, M., & Lauerman, J. (1999). *Living to 100: Lessons in living to your maximum potential at any age* (1st ed.). New York, NY: Basic Books.
- Phelan, E. A., & Larson, E. B. (2002). "Successful aging"—Where next? *Journal of the American Geriatrics Society*, *50*, 1306-1308.
- Pilusa, S., Myezwa, H., & Potterton, J. (2019). Prevention care for secondary health conditions among people living with spinal cord injuries: Research protocol. *BMC Research Notes*, *12*, 179. doi:10.1186/s13104-019-4202-7
- Ploughman, M., Austin, M. W., Murdoch, M., Kearney, A., Fisk, J. D., Godwin, M., & Stefanelli, M. (2012). Factors influencing healthy aging with multiple sclerosis: A qualitative study. *Disability and Rehabilitation*, *34*, 26-33. doi:10.3109/09638288.2011.585212
- Putnam, M. (2014). Bridging network divides: Building capacity to support aging with disability populations through research. *Disability and Health Journal*, *7*, S51-S59. doi:10.1016/j.dhjo.2013.08.002
- Putnam, M. (2017). Extending the promise of the Older Americans Act to persons aging with long-term disability. *Research on Aging*, *39*, 799-820. doi:10.1177/0164027516681052
- Putnam, M., Molton, I. R., Truitt, A. R., Smith, A. E., & Jensen, M. P. (2016). Measures of aging with disability in US secondary data sets: Results of a scoping review. *Disability and Health Journal*, *9*, 5-10. doi:10.1016/j.dhjo.2015.07.002
- Rafii, M. S., & Santoro, S. L. (2019). Prevalence and severity of Alzheimer disease in individuals with Down syndrome. *JAMA Neurology*, *76*, 142-143. doi:10.1001/jamaneurol.2018.34432714717
- Rejeski, W. J., Miller, M. E., Foy, C., Messier, S., & Rapp, S. (2001). Self-efficacy and the progression of functional limitations and self-reported disability in older adults with knee pain. *Journals of Gerontology: Series B. Psychological Sciences & Social Sciences*, *56*, S261-S265. doi:10.1093/geronb/56.5.S261
- Rosvall, M., & Bergstrom, C. T. (2010). Mapping change in large networks. *PLoS ONE*, *5*(1), e8694. doi:10.1371/journal.pone.0008694
- Rosvall, M., & Bergstrom, C. T. (2011). Multilevel compression of random walks on networks reveals hierarchical organization in large integrated systems. *PLoS ONE*, *6*(4), e18209. doi:10.1371/journal.pone.0018209
- Rote, S. M., & Moon, H. (2018). Racial/ethnic differences in caregiving frequency: Does immigrant status matter? *Journals of Gerontology: Series B. Psychological Sciences & Social Sciences*, *73*, 1088-1098. doi:10.1093/geronb/gbw106
- Roth, D. L., Brown, S. L., Rhodes, J. D., & Haley, W. E. (2018). Reduced mortality rates among caregivers: Does family caregiving provide a stress-buffering effect? *Psychology and Aging*, *33*, 619-629. doi:10.1037/pag0000224
- Rowe, J. W., & Kahn, R. L. (1987). Human aging: Usual and successful. *Science*, *237*, 143-149.
- Rowe, J. W., & Kahn, R. L. (1997). Successful aging. *Gerontologist*, *37*, 433-440.
- Rowe, J. W., & Kahn, R. L. (2015). Successful Aging 2.0: Conceptual expansions for the 21st century. *Journals of Gerontology: Series B. Psychological Sciences & Social Sciences*, *70*, 593-596. doi:10.1093/geronb/gbv025

- Smith, E. M., Boucher, N., Miller, W. C., & Team, S. R. (2016). Caregiving services in spinal cord injury: A systematic review of the literature. *Spinal Cord*, *54*, 562-569. doi:10.1038/sc.2016.8
- Strauss, D. J., Devivo, M. J., Paculdo, D. R., & Shavelle, R. M. (2006). Trends in life expectancy after spinal cord injury. *Archives of Physical Medicine and Rehabilitation*, *87*, 1079-1085. doi:10.1016/j.apmr.2006.04.022
- Swerissen, H., Belfrage, J., Weeks, A., Jordan, L., Walker, C., Furler, J., . . . Peterson, C. (2006). A randomised control trial of a self-management program for people with a chronic illness from Vietnamese, Chinese, Italian and Greek backgrounds. *Patient Education and Counseling*, *64*, 360-368. doi:10.1016/j.pec.2006.04.003
- Tinker, A., Hussain, L., D'Cruz, J. L., Tai, W. Y. S., & Zaidman, S. (2016). Why should medical students study Social Gerontology? *Age and Ageing*, *45*, 190-193. doi:10.1093/ageing/afw003
- Verbrugge, L. M., Latham, K., & Clarke, P. J. (2017). Aging with disability for midlife and older adults. *Research on Aging*, *39*, 741-777. doi:10.1177/0164027516681051
- Wang, Z. X., Ma, C. Y., Han, H. J., He, R. L., Zhou, L. Y., Liang, R. F., & Yu, H. M. (2018). Caregiver burden in Alzheimer's disease: Moderation effects of social support and mediation effects of positive aspects of caregiving. *International Journal of Geriatric Psychiatry*, *33*, 1198-1206. doi:10.1002/gps.4910
- Whitney, D. G., Hurvitz, E. A., Devlin, M. J., Caird, M. S., French, Z. P., Ellenberg, E. C., & Peterson, M. D. (2018). Age trajectories of musculoskeletal morbidities in adults with cerebral palsy. *Bone*, *114*, 285-291. doi:10.1016/j.bone.2018.07.002
- Wolf, D. A., Freedman, V. A., Ondrich, J. I., Seplaki, C. L., & Spillman, B. C. (2015). Disability trajectories at the end of life: A "countdown" model. *Journals of Gerontology: Series B Psychological Sciences & Social Sciences*, *70*, 745-752. doi:10.1093/geronb/gbu182
- World Health Organization. (2001). *International Classification of Functioning, Disability and Health (ICF)*. Geneva, Switzerland: Author.
- Young, H. J., Mehta, T. S., Herman, C., Wang, F. C. C., & Rimmer, J. H. (2019). The effects of M2M and adapted yoga on physical and psychosocial outcomes in people with multiple sclerosis. *Archives of Physical Medicine and Rehabilitation*, *100*, 391-400. doi:10.1016/j.apmr.2018.06.032