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To cite this article: Michelle Putnam (2012) Can Aging with Disability Find a Home in Gerontological Social Work?, Journal of Gerontological Social Work, 55:2, 91-94, DOI: [10.1080/01634372.2012.647581](https://doi.org/10.1080/01634372.2012.647581)

To link to this article: <https://doi.org/10.1080/01634372.2012.647581>



Published online: 10 Feb 2012.



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## Introduction

# Can Aging with Disability Find a Home in Gerontological Social Work?

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I am deeply grateful to Dr. Amanda Barusch, Editor, and Dr. Carmen Morano, Managing Editor, for enthusiastically supporting this special issue of the *Journal of Gerontological Social Work (JGSW)* on aging with disability. This issue is timely, the contributors are notable experts in fields of aging and disability, and, collectively, the articles make a strong argument for why the field of gerontological social work should widen its umbrella to include issues of aging with disability under its scope of research, policy, and practice. I encourage readers to review all of the articles in this special issue because, as I hope they will agree, there is real potential for social work to provide leadership in this area of clinical, program, and policy practice.

To help introduce aging with disability, in the following I offer a few descriptions of people who are aging with disability and concerns they might have relevant to gerontological social work: (a) the 67-year-old individual who caught the polio virus as a child in the 1950s, lived with minor to major functional impairment for most of her life, and is now experiencing secondary conditions such as fatigue, pain, and muscle weakness and needs to retire early; (b) a 64-year-old person with developmental/intellectual disabilities who seeks retirement and new friends after working full time in a sheltered workshop and is living independently for the first time after his parents died; (c) a 58-year-old military veteran with traumatic brain injury who received acute emergency care that permitted accident survival, now seeks productive and meaningful engagement with his family and in society as he grows older; (d) a 74-year-old individual with significant, chronic mental illness who is negotiating spousal caregiving and grandparenting and needs assistance managing her own health and wellness needs; e) a 72-year-old Deaf individual (identifying as a linguistic minority) struggles

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to find a geriatrician's office that uses American Sign Language. These are just a few examples of where disability, aging, and disability with aging intersect. Although there is, arguably, a uniqueness to aging with disability (different than incurring disability for the first time at older ages), the aging with disability population is thought to be quite large—likely several million individuals—so there are common experiences. Unfortunately, we have no representative population demographic data to date. Only a few nationally representative surveys collect information about age of diagnosis, onset of impairment or duration of disability, which is required to identify the subgroup aging with disability. Those that do have versions of some of these measures are just beginning to be analyzed by researchers.

In the larger picture, research on aging with disability dates back about 50 years to the 1960s—associated with the creation of University Affiliated Programs by Congress (PL 88–164; now called University Centers for Excellence in Developmental Disabilities or UCEEDs) which are funded through the Administration on Developmental Disabilities, a unit of the Administration for Children and Families within the United States Department of Health and Human Services. Dedicated research programs on aging with physical disability began in earnest with the establishment of the National Institute on Disability and Rehabilitation Research (NIDRR) as part of the 1978 amendments to the Rehabilitation Services Act of 1973. NIDRR is located within the Office of Special Education and Rehabilitative Services, United States Department of Education. Research on aging (which has included study of disability at older ages) has been supported by the National Institutes of Aging since its founding in 1974. A quick literature review in PubMed will show that there are thousands of articles on aging, disability, and even many hundreds on aging with disability. That is to say, that there is extant knowledge about aging with disability and substantial independent knowledge about aging and disability as well as aging into disability. So why pose the question of whether aging with disability can find a home within gerontological social work? And why this special issue? Does aging with disability already have a home?

The answer to these questions can be complex, but they are also rather simple from my perspective—gerontological social work is a good fit for research and practice related to aging with disability. To briefly address the more complex answer, I think the study of aging with disability and professional practice with persons aging with disability, their families, and communities, requires a multidimensional understanding of the person and the environment or, differently said, a bio-psycho-social perspective. This multidimensional perspective is a defining trait of the social work field, and one that is much needed for building knowledge about, and engaging in, professional practice with the aging with disability population. Much of existing research and practice related to aging with disability has occurred

within the fields of medicine, rehabilitation, psychology, and economics—and each discipline tends to splinter the individual into smaller components, not focusing on the whole person. For instance, larger issues like family roles, work life, and community engagement and participation, as well as more traditional gerontological social work issues including long-term supports and services, independent living, retirement and financial planning, health care access and adequacy, and caregiver supports and resources are often overlooked or minimally addressed. But a social work perspective, a more wide-angle look, by default considers the whole person and even extends the view to examine issues of human rights and social and economic justice. Moreover, due to its interdisciplinary nature, there is great capacity within the field of gerontological social work to build bridges across disciplines, fields of practice, and consumers/clients to facilitate collective problem solving across levels. It strikes me, that few, if any, other professionals are so well-suited to be leaders in the area of aging with disability research, policy, and practice.

A challenge for gerontological social work is that individuals aging with disability are not our traditional consumers or clients. Most gerontological training focuses on older adults who are aging into disability. Thus, we tend to have a lack of familiarity with everything from the symptoms of early and mid-age onset diseases to philosophies and theories of disability to funding and structures of disability support and service systems. Additionally, we are often less aware of the short- and long-term effects disability-related socio-economic, health, and political disparities can have on individuals and their families. Finally, the organizations, systems, and policies that work are typically designed for adults aging into disability all the way from mission statements to program delivery options. That said, I think the time is right for gerontological social work to step up to the challenge of widening its scope to include the population of adults aging with disability. There is a tremendous amount of work to be done in helping to facilitate positive and meaningful aging experience—or a *good old age*, however it might be individually defined—for individuals and their families.

This opportunity is made clear by the contributions to this special issue, which converge around the area of health care and long-term care supports and services—an area where profound policy shifts are occurring that directly impact persons aging with disability. This issue opens with a contribution by Dr. Jeppsson Grassman and colleagues, who explore the idea that there is a life-long signature of disability for individuals as they age in which time and change play central roles. Then Dr. Margaret Campbell, of NIDRR, pairs with Drs. Michelle M. Washko and Jane Tilly, of the Administration on Aging, to call for greater attention, support, and alignment of federal activities to facilitate research to practice pathways that support individuals both aging with and aging into disability. Next, Dr. Sarah Ruiz and colleagues report on how persons aging with disabilities fair under the Centers

for Medicare and Medicaid Services (CMS) efforts to more equitably provide community-based long-term care supports and services, compared to institutional services using CMS Rebalancing Indicators data. Taking a different tack, Dr. Nicole Ruggiano discusses the importance of paying attention to bias against older adults aging into disability in consumer-directed home and community-based programs. Research highlighting the importance of supporting caregivers of military veterans, a growing subgroup of persons aging with disability, through flexible respite care programs is presented by Dr. Sherri L. LaVela and her collaborators. The final two articles in this special issue have at their centers the key role of gerontological social workers. Ms. Laura M. Robinson and her co-authors argue that gerontological social workers are the lynchpin for addressing health disparities found among the population of persons aging with developmental/intellectual disabilities, and Drs. Sara S. Bachman and Judith G. Gonyea highlight the opportunities for gerontological social workers to advocate for and engage in improving practices for persons aging with disability who are dually eligible for Medicaid and Medicare insurance benefits.

I would be remiss if I did not mention three additional manuscripts related to aging with disability that appeared in the *JGSW* in 2011. Contributions by Cummings and Kropf (2011) on aging with severe mental illness, Finlayson and Cho (2011) on support group use and need for persons aging with multiple sclerosis, and Harrison and colleagues (2011) on the meaning of gender while aging with paralytic polio, helped pave the way for this special issue and are worthy of a reader's time and attention.

In closing, I hope this special issue succeeds in making the case that aging with disability can find a home in gerontological social work. And, I hope that *JGSW* readers gain knowledge, insight, and a curiosity about aging with disability from this issue that then generates strong social work leadership in this area of practice.

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