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Commentary

Bridging network divides: Building capacity to support aging with disability populations through research

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Abstract

Federal and state efforts to rebalance long-term services and supports (LTSS) in favor of home and community based over institutional settings has helped create structural bridges between the historically separated aging and disability LTSS networks by integrating and/or linking aging and disability systems. These changes present new opportunities to study bridging mechanisms and program related outcomes at national and local levels through federally sponsored LTSS initiatives termed Rebalancing programs. Rebalancing programs also offer opportunities to explore and understand the capacity of LTSS networks (age integrated or linked aging and disability systems) to serve aging with disability populations, persons who live with long-term chronic conditions or impairments such as multiple sclerosis, spinal cord injury, intellectual or developmental disabilities. To date, there is limited evidence based LTSS program and practice knowledge about this heterogeneous population such as met and unmet needs or interventions to support healthy aging. Efforts that center on bridging the larger fields of aging and disability in order to build new knowledge and engage in knowledge translation and translational research are critical for building capacity to support persons aging with disability in LTSS. Generating the investment in bridging aging and disability research across stakeholder group, including researchers and funders, is vital for these efforts.

Keywords: Aging; Disability; Long-term services and supports; Public policy; Bridging

Building capacity in LTSS to support persons aging with disability through bridging research

Programs and policies that provide long-term services and supports (LTSS) to adults in the United States (US) are usually segmented by age of the consumer (18–59 or 64, and age 60 or 65 and older) and nature of disability (e.g. developmental/intellectual, physical, and psychiatric), creating categorical service systems. This historical practice has created silos dividing aging and disability policies, programs, and consumers at federal, state, and local levels into distinct service recipient groups.[1] Categorical segmentation both helped generate and has been reinforced by distinct fields of scholarly research and professional training that respectively build knowledge for, and prepare practitioners to work within, specialized and divided aging and disability LTSS systems.[2] This silo system has produced age-based theories and conceptual frameworks, bifurcated scientific knowledge bases, parallel fields of professional practice, and system-specific ideologies, vocabularies, and cultures of service delivery that have been described in extensive detail.[3,4] Elements such as program eligibility, organizational missions of service providers and professional training of their staff, and consumer-identification as either older or disabled all add to the synergy that sustains the silo system.[2]

But the landscape on which aging and disability silos are built is rapidly changing. Federally sponsored "Rebalancing" program initiatives are actively attempting to break down silos and build structural bridges across aging and disability LTSS networks, particularly targeting Medicaid and Older Americans Act (OAA) programs. Federal Rebalancing program initiatives aim to reduce institutional long-term care use and increase use of home and community-based services (HCBS),[5,6] and prioritize community living, a shared value between aging and disability fields of practice, policy, and scholarship. These initiatives contain mechanisms that mandate cross-network collaboration with the aim of reorganizing supports and services into more integrated and coordinated networks. As these bridges take shape, the potential for building new

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knowledge and supporting knowledge translation and translational research across the fields of aging and disability increases. The need for this type of knowledge bridging is substantial in order to support the needs of persons aging with long-term disability. The growing aging with long-term disability populations includes persons with onset of impairment and chronic conditions in early or mid-life such as multiple sclerosis, spinal cord injury, cerebral palsy, rheumatoid arthritis, traumatic brain injury, developmental or intellectual disability, and oral speech, auditory and sensory limitations.

There is very modest evidence-based program and practice knowledge about LTSS and persons aging with disability. One effect of the silo system has been the reinforcement of specialized practice and research domains that typically focus on either older adults or younger people with disabilities, but not both. Although less age-based models of care and service delivery, such as person-centered care,[7] are being more widely implemented in HCBS programs, few practitioners working within those programs are likely to be trained in both the fields of aging and disability, resulting in limited expertise working across populations. Even for those who have this dual experience, the lack of research relating to aging with disability and LSS remains problematic, particularly as LTSS professionals tend to think of older adults and younger persons aging with disability as qualitatively different consumers with differing aging-related needs.[8] Fostering new knowledge development and knowledge translation can help to answer important global questions about providing LTSS to persons aging with disability such as: How does aging with long-term disability differ from aging into disability in later life? What types of LTSS do persons aging with disabilities need that are not currently found within existing aging or disability networks? How can existing LTSS and health and wellness interventions designed for younger adults with disabilities or older adults aging into disability be transferred to persons aging with disabilities? In what areas do new interventions need to be developed? What measures need to be included in administrative and programmatic data collection systems to better capture the disability status and LTSS needs, including assistive technologies, of individuals both aging with and aging into disability at different stages of the life course? What types and levels of professional training are needed to work with aging with disability populations and how might that differ from training and education already provided? and, which HCBSs are best provided within disability services systems, aging service systems or some combination of both?

Background for bridging aging and disability research in LTSS

In simple terms, the practice of bridging brings the fields of aging and disability together by creating pathways across fields for sharing existing and developing new knowledge in areas of professional practice, policy, and research.[9] A definition of bridging aging and disability was recently articulated by the authors of the Toronto Declaration on Bridging Knowledge, Policy and Practice in Aging and Disability:

> Bridging encompasses a range of concepts, tasks, technologies and practices aimed at improving knowledge sharing and collaboration across stakeholders, organizations and fields of care and support for persons with disabilities, their families, and the aging population. Bridging tasks include activities of dissemination, coordination, assessment, empowerment, service delivery, management, financing and policy.[10]

Structural bridging efforts between aging and disability service systems date back several decades. In their recent review of bridging between aging and developmental disabilities networks, Factor, Heller, and Janicki[3] cite several important markers of formal bridging efforts by state and federal administrators. A premier program example of bridging aging and disability is the Cash and Counseling demonstration (1998–2009), which evaluated participant-directed Medicaid HCBS.[11] Cash and Counseling was a high profile effort to test use of the disability model of consumer-direction with both older and younger clients. Supported by a private–public collaboration by the Robert Wood Johnson Foundation, the Office of the Assistant Secretary for Planning and Evaluation (ASPE) in the United States Department of Health and Human Services (HHS), the Centers for Medicare & Medicaid Services (CMS), Cash and Counseling findings deemed consumer-direction to be a viable program option with successful outcomes.[11]

Knowledge development and translation efforts have also been building slowly over time across fields of study. Examples include clinical research articulating physiological changes and related assistance needs based on duration of spinal cord injury[12] and accelerated aging,[13] assistive technology research focusing on maintaining function over several decades,[14] and research related to supporting individuals with intellectual disabilities and their families over the life course.[15] The National Institute on Disability and Rehabilitation Research (NIDRR) has been a primary funder of this research, supporting Rehabilitation and Research Training Centers (RRTCs) and Rehabilitation Engineering Research Centers (RERCs) on aging with disability.[16] The National Institutes of Health has also supported numerous studies on aging with disability through investigator-initiated research programs. While this funding has supported a growing body of research directly focusing on aging with disability, much of it is specific to individual diagnostic groups. Only a limited amount of scholarship focuses on LTSS need or use across aging with disability populations.

Recently, however, several national and international professional conferences have focused on developing agendas