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The Aging and Developmental/Physical Disabilities Networks:

Can the Silos Be Dismantled?

by Lenard W. Kaye, Lucille A. Zeph, and Alan B. Cobo-Lewis

The service networks for aging, on the one hand, and developmental and physical disabilities, on the other hand, traditionally have functioned in distinctly separate camps. There are a variety of reasons for this including the historical emphasis of disability services and policies on addressing issues of a consumer population that has been primarily comprised of children, youth, and younger and middle-aged adults, while aging services and policies have focused on individuals in their sixties and beyond regardless of the presence of a disability.

The traditional focal points of the two service networks on different age groups has influenced, in large part, their priorities, programs, and educational and research foci. The fact is that, in the past, the disability services community rarely needed to address how someone would manage their developmental or physical disability in old age because such individuals rarely survived beyond middle age. And because they rarely survived beyond middle age, the service system for older adults was also not originally conceived as needing to be particularly responsive to individuals with long-term developmental or physical disabilities. The conceptualization of nonoverlapping populations has resulted in separate public policies and in varying degrees of isolation, territorialism, and specialization across the two service networks (Putnam 2007).

Historically, the aging and disabilities networks have developed and worked independently of one another. In fact, this independent planning and programming was presumed to be the preferred and most effective approach given what were perceived to be population groups with different, if not unique, needs, interests, and challenges. However, medical advances, lifestyle improvements, and increasingly inclusive philosophies of community life and well-being have, in recent years, compelled us to question and rethink the traditional paradigm.

Change is in the air—presumably as much for reasons of economy and effectiveness as for increased philosophical alignment. At the federal level, the Administration for Community Living (ACL) was established in April 2012 to address the needs of people with disabilities and older adults. Under the ACL roof are both the Administration on Aging and the Administration on Intellectual and Developmental Disabilities as well as the Health and Human Services (HHS) Office on Disability (among other units). The mission of the ACL is to maximize the independence, well-being, and health of older adults, people with disabilities across the lifespan, and their families and caregivers. As the name suggests, the emphasis is on increasing access to community supports for all Americans so that they can fully participate in all aspects of their communities. At the

state level, similar administrative restructuring has occurred. Maine's Office of Elder Services has been combined with the Office of Adults with Cognitive and Physical Disabilities to form the Office of Aging and Disability Services (OADS). Consistent with the integration of direct community services offered to Maine's older adults by the Aging and Disability Resource Centers, this merger was intended to improve coordination and integration, create more effective access, reduce duplication of effort, and improve individual outcomes.

Are there compelling reasons to encourage aging and disabilities network crossover outside of federal and state government? Are there factors that would discourage integration? Should we be wary about such philosophical and organizational changes?

THE CASE FOR NETWORK CROSSOVER

The Power of Coalitions

Aligning one's interests with those of another group has undeniable political and strategic advantages. In an age of scarce resources, a single voice advocating for the universal needs of individuals who are both aging and disabled can't help but to create greater leverage when negotiating with decision makers. There is undeniable strength in numbers, and the rapidly increasing number of older adults, when combined with the total number of individuals with disabilities, has the potential to be a strong force for change.

The Appeal of Inclusiveness

History has documented that segregation runs the risk of promoting fear and suspicion among individuals and groups. It can encourage an "us versus them" mentality. Policies and programs

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that are premised on inclusiveness tend to promote diversity and equity while minimizing discrimination and bias. Inclusive policies and programs aim to avoid excluding or marginalizing anyone from the benefits, opportunities, and resources to be derived from particular initiatives (BBI 2012). Such policies are more likely to be welcoming to all individuals and embrace diversity more broadly. The combined efforts of the aging and disability networks will enhance all efforts towards creating inclusive communities.

Common Human Needs

Access to needed health and medical services, housing that enables individuals to live safely and securely and remain in their communities, transportation that is accessible and affordable, and opportunities for community and social engagement are both desired and needed by all citizens whether or not they are living with a disability and regardless of age. These are universal human needs and, when available and accessible, result in vastly improved quality of life and well-being.

Long-Term Care and Working with Caregivers to Cross Lines

In the quest for common ground, one of the more compelling arguments for crossing aging and disability network lines is to promote services and supports in the long-term care arena. The National Council on Aging (NCOA), for example, has successfully led a coalition of some 35 national aging and disability organizations—including AARP, the American Association of People with Disabilities, and the Association of University Centers on Disabilities—to advance long-term care services for older adults and individuals with disabilities. The Disability and Aging Collaborative,

formed during health reform, represents one of the first large-scale efforts to bring the aging and disability communities together. It aims to show that advocacy efforts across the two networks can be coordinated and address improving access to home- and community-based services (HCBS) at the same time that consumer engagement, protections, and quality are enhanced.

Aging adults and people with developmental disabilities commonly rely on informal caregivers. For aging parents, these informal caregivers are frequently their adult children. For adults with physical or developmental disabilities, these informal caregivers are frequently their parents—who become less able to provide informal care as they grow older. In both the aging and disability arenas, informal caregivers need support, and informal caregivers of adults with developmental disabilities may need additional support as they, themselves, age.

Universal Access and the Age-Friendly Community Movement

There is considerable discussion in the United States and across the globe advocating for the establishment of age-friendly communities. The World Health Organization (WHO) has been a strong advocate of the movement aimed at encouraging cities and communities to actively engage in the steps required to ensure that people of all ages are able to participate in community activities. An age-friendly community is a city or community that makes it easy for older adults to stay connected to those they care about, remain healthy and active, and receive the support they need. An age-friendly community makes deliberate decisions and commitments to ensure that the physical environment and the organizational infrastructure

and available services are responsive to older adults. Age-friendly communities promote health by being accessible, equitable, inclusive, safe, and supportive (WHO 2007). It stands to reason that the characteristics of a community that is responsive to older adults will be responsive to the needs of disabled persons as well, given the universality of the principles that define a community as being age-friendly. For that matter, age-friendly communities are likely to be responsive to the needs of individuals (and families) of all ages whether or not they are older or disabled.

It is worth noting that communities specifically tailored to be age-friendly could conceivably be seen by some as not being welcoming or friendly to people with developmental disabilities and other age groups. The argument could therefore be made that the establishment of inclusive communities that are not deliberately focused on the needs and wants of older adults, but are inclusive of and friendly to older adults and all other community groups, may send an even more powerful message that runs little risk of being misinterpreted.

Risk of Dementia

Depending on a number of aggravating and mitigating factors, aging adults may be at risk of developing some form of dementia, including Alzheimer's disease. Estimates of the risk of dementia in individuals with developmental disabilities diverge, but it may be comparable to or higher than the risk among people without developmental disabilities (Strydom et al. 2010). Specific subgroups can have a different profile. In particular, persons with Down syndrome are at substantial risk of developing Alzheimer's at a comparatively early age (Coppus et al. 2006; Tyrrell et al. 2001). Awareness of issues such as the

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importance of screening for dementia is thus important in the arenas of aging and developmental disabilities—but the issues can be subtle. For this reason, it is an area in need of further research and information sharing to foster the use (NTG 2013) and further development (Zeilinger, Stiehl, and Weber 2013) of screening tools for dementia that are tailored to individuals with developmental disabilities.

A CAUTIONARY NOTE

Disability: A Matter of Degree and Functional Impact

Few individuals can claim not to have some physical or developmental condition that has an impact on their life. More significant perhaps is the extent to which such conditions actually limit one's functional capacity to perform a variety of activities of daily living. One in five persons (19 percent) reports a disability according to the 2012 news release by the U.S. Census Bureau. However, between the ages of 65 and 75 years, only 3.3 percent of the noninstitutionalized population needs help with personal care. This rises to 10.5 percent for those individuals 75 years and older. On the other hand, 61.1 percent of persons 65 years and older report having difficulty with at least one basic action or are limited in terms of performing one complex activity. According to the Centers for Disease Control and Prevention (CDC), that's approximately 26 million people in the United States. People in the oldest age group—80 and older—are almost nine times more likely to have a disability than those in the youngest group (younger than 15) (71 percent compared with 8 percent). While the probability of having a severe disability is only one in 20 for those 15 to 24 years of age, it increases to one in four for those 65 to 69 years old.¹

It is clear that a large majority of older adults live without significant disability. Most lead active and independent lives. Likewise, individuals with intellectual and developmental disabilities, regardless of age, also seek to live independently, but are often limited by environmental and attitudinal barriers. But, herein lies the rub. Simply put, not all disabled individuals are old—and not all older adults are disabled. Nor do all older adults generally, or older adults living with a disability in particular, need additional levels of assistance and support.

Complicating the discussion about network crossover are trends confirming that most gains in life expectancy have been accompanied by declining rates of mortality and the compression of morbidity (shortened time periods that adults live with chronic conditions). Disability incidence rates among older adults have declined, resulting in decreases in older adults with functional impairment caused by a chronic disease or physical condition (Putnam and Stark 2010).

Increases in life expectancy—and increases in *disability-free* life expectancy—have been linked both to delays in the onset of disability and to increments in the rate of recovery from disability (He and Larsen 2014). Current trends that reflect the compression of morbidity—and continued emphasis on healthy, active, and productive aging—may serve to slow or temper the aging and disability crossover process. The current public discourse has emphasized vital aging and the impressive later-life capacities of most of the baby boomer generation. As the boomers redefine the aging experience, it may result in a tendency to distance, or at least separate in some respects, growing older from the experience of living with a disability or impairment. Nevertheless, the rapid

expansion in the number of older adults is expected to result in increases in the absolute number of older adults living with disabilities.

Endorsing a Collaborative Perspective

In the final analysis, we can't help but endorse increased alignment of the aging and disability networks in all arenas, including policy making, program development, education, and research. Undeniable population trends including the survival of individuals with developmental and physical disabilities into later life, the reality of common and universal human needs, the desirability of inclusive thinking, and the strategic advantage to be realized when special interest populations ally themselves all make for a powerful argument in favor of increasing network crossover activities. Because Maine has the oldest population in the nation and one of the highest prevalence rates for physical disability, the state should be in the forefront of initiatives that advance a philosophy of network crossover. While not without its challenges, strong recognition of, and respect for, significant diversity in the aging and disability populations will guard against overly simplistic blanket solutions when it comes to developing policies and programs that meet the needs and wants of both population groups.

The University of Maine is well positioned to test the waters associated with strategic integration of the aging and disability networks. We anticipate that the presence of two well-established interdisciplinary research centers at the University of Maine—the Center on Aging and the Center for Community Inclusion and Disability Studies (Maine's federally designated University Center for Excellence in Developmental

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Disabilities)—will serve as excellent venues and programmatic test beds for increased collaboration and the discovery of common ground in the arenas of aging and disabilities education, research, and service in the years ahead. A coordinated effort between these two centers could help break down the barriers within the aging and disability communities and create services and supports that are universally accessible and that contribute to enhancing the quality of life for all Maine citizens. 🐟

ENDNOTES

1. The U.S. Census Bureau news release is available at <https://www.census.gov/newsroom/releases/archives/miscellaneous/cb12-134.html> and the statistics from the CDC are available at <http://www.cdc.gov/nchs/fastats/disability.htm>

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