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Policy Concerns Raised by the Growing U.S. Population Aging with Disability

Lisa I. Iezzoni, MD, MSc

Mongan Institute for Health Policy, Massachusetts General Hospital Harvard Medical School, Boston, MA

Narrative Summary

The number of Americans aging with disabilities will grow substantially in coming decades. Promulgating policies and practices to improve their independent functioning within communities and participation in daily life is therefore imperative, but the most effective approaches for meeting various needs are generally unknown. Historically, research addressing approaches targeting elderly individuals have differed in important ways (e.g., underlying models of disability) from studies involving younger persons aging with disabilities. Participants in a conference addressing this discordance identified six major areas requiring study: (1) resources to support independent living; (2) improving quality of life and participation in daily activities; (3) performing activities of daily living (ADL) and instrumental ADLs; (4) role of families; (5) medical care; and (6) concerns transcending sectors. As these investigations move forward, bridging the divide between approaches addressing elderly individuals versus persons with disabilities will be critical.

Keywords

disability; aging; health policy

Background

Over the years, both policymakers and scientists have recognized seemingly intransigent schisms between policies and programs serving elderly individuals versus younger populations with disabilities and parallel disjunctures in the research and evidence bases for these two constituencies. In May 2012, representatives from various stakeholder groups met to discuss ways to bridge these historical divides. This article summarizes major policy concerns identified by conference speakers and participants during their two-day meeting. Three agencies sponsored this conference: the newly formed Administration for Community

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Corresponding author: Dr. Iezzoni, Director, Mongan Institute for Health Policy, Massachusetts General Hospital, 50 Staniford Street, Room 901B, Boston, MA 02114. Telephone: (617) 643-0657 Fax: (617) 724-4738. liezzoni@partners.org.

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Living within the U.S. Department of Health and Human Services, the National Institute on Aging, and the National Institute on Disability and Rehabilitation Research within the Department of Education. The federal Interagency Committee on Disability Research served as co-sponsor. The Center for Aging and Policy Studies at Syracuse University and the Center on the Demography of Aging at University of Michigan jointly organized the conference, inviting researchers studying aging and disability with the dual aims of summarizing current knowledge about aging with disability and identifying major research and policy questions.

A companion paper to this policy overview summarizes conference presentations relating to current understanding and knowledge gaps relating to persons aging with disability, defined for our purposes as individuals with long-term disabilities that were present from birth or arose by midlife who now are entering later decades of life (1). This paper summarizes major policy challenges addressed in four conference papers (2-5) and mentioned during discussions among conference speakers and participants. This paper does not provide a comprehensive review of policy concerns raised by growing numbers of Americans aging with disabilities but instead highlights topics identified during the May 2012 conference.

Overarching Context of Policy and Programmatic Issues

Conference papers and discussions noted six main policy and programmatic points described below. Exploring these points, however, requires first examining underlying assumptions about how various programs and policies might affect the lives and quality of life of persons living and aging with disabilities. Individuals in older and younger generations with disabilities generally share the goal of independence: living in communities and participating actively in community life rather than dwelling in structured, highly supervised or institutional settings. Nonetheless, in the context of disability, the word “independence” and phrase “independent living” may mean different things to different generations (age cohorts). These different meanings carry important policy and programmatic implications. Simplifying for brevity and clarity:

- For the older generation (World War II, Great Depression era individuals), “disability” equates with functional impairments preventing “normal” participation in daily activities. In response to functional limitations, individuals must compensate or readjust their expectations about their daily lives. Accommodations, such as assistive technologies (3), represent dependence.
- For younger individuals, such as members of the “baby boom” generation and later generations, disability results from functional impairments confronting environmental barriers to participation. Accommodations, including the physically-intimate assistance of a personal care assistant (PCA) with basic activities of daily living (ADLs), facilitate independence under the assumption of consumer-directed services (5).

These differing perspectives across age cohorts of independence underlie the approaches of disability programs, policies and research, including: distinct age- and disability-based theories and conceptual frameworks; differing perspectives on health and social service

interventions, innovations, and programmatic silos; and different language. When identical and seemingly straightforward words (e.g., “independence,” “independent living,” “dependence,” “freedom”) carry different meanings, this contributes to confusion and misunderstandings across sectors associated with younger individuals with disabilities versus those targeting needs of older populations. This produces inefficiencies that complicate development of services and programs to advance the shared needs of both populations (5).

A critical context enveloping policy discussions is the Americans with Disabilities Act (ADA), signed into law on July 26, 1990. The ADA requires proactive efforts to accommodate disability but within the constraints of “reasonableness” – “reasonable accommodations” and “readily achievable” environmental modifications. The 1999 U.S. Supreme Court decision in *Olmstead v. L.C.* is particularly relevant to addressing the needs of persons aging with disability. In this decision, the court ruled that public agencies must provide community-based services to individuals with disabilities when: (1) these services are appropriate; (2) the individuals affected do not object to community-based services; and (3) provision of community-based services is reasonable, taking into account public resources and other demands on public agencies (http://www.ada.gov/olmstead/olmstead_about.htm). This latter concern – about reasonableness of resources devoted to individuals with disabilities – will likely generate debates given the reality of shrinking state and local budgets and rising federal budget deficits.

The heterogeneity of disabilities and wide diversity of specific accommodation needs complicate responses to *Olmstead* and other ADA-related rulings. For persons aging with disability, the co-occurrence of health conditions associated with aging (e.g., hypertension, diabetes, cardiovascular diseases) – as well as secondary conditions related to disabilities – can result in multi-morbidities that compound and complicate accommodation needs. These complexities occur against a backdrop of social disadvantage and generally poorer health among the population with disabilities, including high unemployment, low incomes and educational attainment, higher smoking and obesity rates, and health care disparities. Even safety net income support programs may not redress income disparities. Responding effectively to the needs of individuals aging with disability will therefore require development of diverse accommodation approaches along with their technical and policy specifications.

These demands require proactive thinking, planning, and thus resources across various sectors (e.g., housing, transportation, telecommunications, health care, social services, etc). The notion of “disability in all policies” – considering the implications of population disability when developing all programs and policies – would concentrate efforts to address diverse needs of this and future generations aging with disability. Given this overall context, six more specific programmatic and policy issues emerged from the conference papers and presentations.

1. Resources to support independent living

Supporting independent living for persons aging with disability will require resources at multiple levels: individuals; families, broadly defined; federal, state, and local governments;

and communities writ large. This need will grow against a backdrop of record federal budget deficits and state and local governments with severely constrained resources. Setting priorities for expenditures of scarce resources will require answers to critical questions, including:

- What are the most efficient ways to achieve independent living among persons aging with disability?
- What is purchased by the dollars currently spent, and what program expenditures might be offset against other types of expenditures to support independent living?
- How are expenditures distributed across subgroups of individuals aging with disability and across different sectors?
- How much is the public willing to pay to support independent living among persons aging with disability?

2. Improving Quality of Life and Participation in Daily Activities

Expanding participation in daily activities in general improves well-being and quality of life of all individuals including persons aging with disability. Increasing these activities can reduce depression and increase persons' self-efficacy; being as physically active as possible can also contribute to reducing secondary conditions related to disability and chronic health conditions of aging (e.g., hypertension, diabetes). Various accommodations facilitate community participation and physical activity, such as assistive technologies to accommodate individual needs (including computer-based and information technologies (3)), home modifications that improve accessibility and safety, and PCAs (5).

The evidence base about strategies to improve community participation and physical activities of persons aging with disability is currently thin, requiring more rigorous investigations (2). Examples of potential study questions include:

- What interventions are most effective at improving quality of life, community participation, and prevention of chronic conditions among persons aging with disability?
- How effective are vocational and other training programs at increasing labor force participation of individuals with different disabilities in the short- and long-term?
- What types of accommodations are most useful for improving quality of life, community participation, and prevention of chronic conditions among persons aging with different types of disabilities?

Each question will require answers that recognize the heterogeneity of disabling conditions and combinations with multi-morbidities. An overall contextual question is whether the public is willing to pay for interventions that primarily target “quality of life” or is some other “return on investment” necessary.

Assistive technology is one area where innovation could yield substantial benefits for improving functioning, independence, and quality of life of persons with disabilities (3). The diversity of disabilities demands wide-ranging consideration of how assistive technology

might serve different population groups. Major areas requiring research include: voice activated equipment of all sorts, including “routine use” equipment (e.g., automated bank teller machines, ticket machines for public transportation); so-called “smart home” technologies; battery technologies and other aspects of wheelchair technologies; limb prostheses; cochlear implants and other hearing technologies; and technologies to improve communication access for persons with impaired vision.

As technology advances, determining how to pay for technology also requires attention. Payment policy issues relating to community-level accommodations, such as the automated bank teller machines or voice-activated kiosks for bus and subway tickets, differ from those relating to technologies for individual-level accommodations (e.g., specialized wheelchairs or communication devices). Many individuals cannot afford out-of-pocket expenditures for assistive technology, and insurance policies typically restrict coverage of technology to narrow categories and “medical necessity” indications. While Medicaid typically covers more assistive technology than does Medicare, Medicaid policies vary by state, and state budget constraints may limit future Medicaid assistive technology coverage. Especially among persons aging with disabilities who are low income, acquiring assistive technology may rank below paying for housing, food, and other essentials.

ADA requirements may dictate the need for certain accommodations, such as the accessibility of public transportation facilities or bank machines. Local governments and businesses must factor these costs into their budgets. The extent to which cost concerns are delaying dissemination of these types of community-based accommodations is unclear, although it is reasonable to conjecture that the recent recession and local governmental budget deficits might slow spread of these assistive technologies. Without these technologies, area residents with disabilities could continue to confront barriers to participation in community activities.

Finally, payment policies might be affecting assistive technology research investments and the development of cutting-edge technologies. The demise of the iBOT mobility aid offers a cautionary example. By using complex gyroscopes and sensors and two sets of powered wheels, this power wheelchair (developed in a partnership between DEKA and the Johnson & Johnson Independence Technology division) could navigate uneven terrains, climb stairs, rise to standing height, among other functionalities. However, because it received Medicare coverage far below its costs, its market was limited: relatively few persons with disabilities could afford to purchase the iBOT on their own. Medicare justified its low pricing by noting that many iBOT features were convenience items and not medically necessary, which is the standard required for Medicare coverage. Independence Technology stopped selling iBOTs in 2009.

3. Performing ADLs and instrumental ADLs (IADLs)

For persons aging with disabilities who have significant physical or cognitive impairments, human assistance with ADLs and IADLs is often essential. While robotic technologies are being developed to serve some of these needs, they are currently far from reality. Informal caregivers – families and friends – are not always available to provide this essential assistance. This absence will be especially felt in future generations as larger numbers of

individuals have no children or fewer children than have prior generations. Personal assistance relationships are complicated. As several conference participants noted, persons with physical disabilities experience relatively high rates of domestic violence and psychological abuse. Parental and other caregivers of individuals with congenital or early occurring physical and intellectual disabilities can also experience abuse or physical injuries in their caregiving roles. Nonetheless, meeting basic ADL and IADL needs is essential to human dignity, health, and well-being.

Medicare does not cover PCA services; Medicaid covers PCAs, but this support varies across states and is at risk with statewide budget constraints. Therefore, significant questions arise concerning PCA needs of persons aging with disability, including:

- What innovative models might offer efficient, effective, and reliable support of ADL and IADL needs?
- How are consumer-directed and other programs that provide PCA care performing from the perspectives of persons with disabilities, PCAs, and agencies funding these services?
- What are projections of PCA needs across aging populations in coming decades, what workforce will be available to meet those needs, and how will they be trained and compensated?

4. Role of families

Across the life course, family roles relating to individuals aging with disabilities are often complicated. Family concerns are especially challenging in the context of intellectual disability, particularly as parents age and then die (4). As mentioned above, domestic abuse rates are relatively high for both women and men with disabilities; sometimes caregivers are also at physical and psychological risk from the individual they assist. Questions about guardianship and self-determination arise, sometimes without clear-cut answers (4). Issues relating to families of individuals aging with disability include:

- What are demographic projections about family composition for persons with disabilities over future decades, and what are the implications for supporting persons aging with disability?
- What approaches best meet the range of support needs of persons aging with intellectual disabilities as their social networks inevitably change?
- What approaches will prevent domestic violence and other abuse of women and men with disabilities and ensure that caregivers' needs are also met?
- How should Health Insurance Portability and Accountability Act (HIPAA) and other privacy and legal concerns be addressed for persons with disabilities in various different circumstances?

5. Medical care

Conference participants clearly eschewed “medicalizing” disability. Nonetheless, especially in the context of an aging population, the need for medical services inevitably arises.

“Medical care” – very broadly defined – is required to address underlying disabling conditions and related secondary conditions, prevent complications and secondary disabilities, and maximize functioning, wellness, and health as it relates to physical, sensory, and emotional functioning. Persons aging with disability are also susceptible to the same chronic conditions often associated with aging, such as hypertension, diabetes, cancers, and cardiovascular disease, as are other individuals. Therefore, concerns relating to medical care require attention, including: fragmentation and poor coordination of care; failure of clinicians from all disciplines to recognize and respect patients' preferences and goals for care; and inaccessible offices, equipment, and communication modalities. Questions about medical services that require more research include:

- How well do innovations in care delivery, such as team-based care, patient-centered medical homes, accountable care organizations, and disease self-management, address needs of individuals aging with disability?
- What strategies for training future health care professionals will best address clinical needs of persons aging with disability? How can clinicians from all disciplines be trained to recognize the needs, perspectives, and preferences of individuals aging with disabilities?
- How does payment policy affect service provision for persons aging with disability? For example, how should payments be adjusted to recognize increased time demands, and what policies should support new delivery models (e.g., global capitation) to improve care coordination?
- What incentives will increase accessibility of health care facilities and practitioners' offices, including in rural communities and including not only physical but also communication access?
- What quality metrics measure care both from technical and patient-centered perspectives? What data are necessary to produce these quality indicators? Are there “human subjects” implications for generating this information among individuals with certain types of disabilities? For example, might privacy be compromised? In addition, collecting data for certain subpopulations (e.g., persons with cognitive impairments, severe mental illness, or needs for communication accommodations) could require special attention.

6. Concerns transcend sectors

As noted earlier, the phrase “disability in all policies” reasonably summarizes an important reality: disability concerns transcend the health and social services sectors, bearing implications for programs relating to income support, housing, transportation, food, labor, education, legal and civil rights, local and regional planning, and so on. Furthermore, disability is part of life. Virtually everyone will experience some type of disability at some point as they age. Therefore, the final set of questions transcends sectors:

- How does society at large plan for growing numbers of persons aging with disabilities?

- What nations offer examples about doing this well and from which the U.S. could learn?
- How can U.S. policymakers meaningfully and measurably introduce the “disability in all policies” perspective?
- What are the societal costs of *not* planning ahead?
- Finally, how can policymakers productively overcome human nature: the inherent reluctance to discuss topics, such as disability, that feel uncomfortable or overwhelming but will, almost inevitably, affect everyone to some extent as they age (6)?

Conclusions

The number of U.S. residents aging with disabilities will grow substantially in coming decades (1). Promulgating policies and practices to improve their independent functioning within communities and participation in daily life is therefore imperative. The notion that disability considerations transcend all sectors expands widely the range of policies and practices that require review and evaluation for their impact on persons aging with disability. During the two-day conference described here, participants could therefore only scratch the surface – much more work is required to delineate the range of areas that need further exploration to improve the experiences of persons aging with disability. This paper suggests topics largely related to health and identifies a variety of areas that require research. As these investigations move forward, it will be critical to bridge the historical divide between studies addressing elderly individuals and persons with disabilities.

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