Aging and Disability: Crossing Network Lines

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Editor

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Preface

Aging, developmental disability, and physical disability service networks are commonly fragmented and loosely organized. Organizations in these networks typically serve one specific consumer population—older adults, people with developmental disabilities, or people with physical disabilities. When consumer population needs “crossover” networks, such as in the case of a person with a spinal cord injury turning 60 and becoming eligible for old-age services, or when a 75-year-old adult with osteoarthritis becomes eligible for personal attendant services provided through a state disability services department’s independent living program, often the cracks both within and across service networks become evident. In summation, aging services were not initially designed with persons aging with significant, long-term disabilities in mind. Services for those with disabilities, developmental or physical, were not designed to address issues of aging. However, due to medical advancements and program changes, this crossover is happening more often than ever before. There is no reason to assume either trend will change. Instead, there are many indicators that this diversification of the older population by disability experience will continue, as will the blending of aging and disability services.

For professionals working with aging, developmental disability, and physical disability networks, changing populations and programs often result in frustration. Even the most well-intentioned professional is often unable to bridge service network gaps due to restrictions in program eligibility based on age or disability status and organizational capacity to engage in partnering or collaborative activities that promote shared resources and knowledge. Persons with disabilities, both older and younger, often experience excessive consumer burden under these circumstances. This is particularly true for adults aging with disabilities, whether physical or developmental, acquired in early- or mid-life. Persons aging with disabilities are often caught between aging and disability
service networks, with neither service system exactly meeting their needs. As aging service consumers, they commonly engage in the additional roles of educator, advocate, and policy expert as they attempt to teach professionals working within service systems about their unique aging-related needs, lobby for inclusion in programs and coverage by enrollment criteria, and interpret the finer details of both private and public policies that regulate entrance, payment, and duration of service receipt. Adults who first experience disability in old age also engage in these activities, though this happens primarily when they attempt to access services that reside within disability service networks.

Our current aging and disability service systems are products of the historical separation of public policies for older and younger adults with disabilities and the isolation, territorialism, and specialization it creates between service programs and the professionals who staff those programs. The need to bridge these gaps between service networks and network professionals is of growing concern for several reasons, including the growing numbers of people aging with disabilities, recent consumer and policy trends that preference choice and consumer-direction for persons of all ages, and the increased institutionalization of community-based services as a normative model of independent living and long-term care service delivery. Despite the push of these factors, cross-network collaborations are frequently less successful than they need to be if they are to reduce the excess burden consumers feel. Sorting out the issues lying at the heart of the difficulties is critical to creating solutions to address them.

From 2002 to 2004, through a Hartford Faculty Scholars Program grant provided by the John A. Hartford Foundation, I conducted an exploratory case study in Missouri to identify both the facilitators and barriers involved in working across aging and disability service networks for professionals. Results from this qualitative study were presented twice in dedicated professional forums. Findings were first presented in April 2004 at a meeting of local Missouri professional stakeholders who evaluated the content validity of the findings, discussed their importance and applicability, and identified future steps for collaboration. The same study findings, along with outcomes of the April 2004 meeting, were presented in October 2004 at the Crossing Network Lines conference held in St. Louis, Missouri, and funded jointly by the National Institute on Aging, and the Center for Social Development and George Warren Brown School of Social Work, both of Washington University in St. Louis. The meeting brought together national experts and professionals in the fields of aging, developmental disability, and physical disability to discuss critical issues in working across service systems and conducting research to further knowledge in this area. Both the study and the two conferences built upon work done at the Wingspread Conference held in
Racine, Wisconsin, in 1985—the first national meeting convened to discuss issues of collaboration between aging and disability consumers and professionals (Mahoney, Estes, & Heumann, 1986).

This volume does not contain conference proceedings from these events. Rather, it draws together the research findings, outcomes of the forums, and expert opinion into a comprehensive analysis of the issues involved in working across aging, developmental disability, and physical disability service networks. In section 1, my coauthors—Anneliese Stoever and Suzanne Pritzker—and I present an introduction to the issues, findings from the case study in Missouri, and outcomes of the April and October meetings. Additionally, Kirsten Dunham, a professional stakeholder currently working across aging and disability network lines, provides commentaries regarding the current challenges they face in their endeavors. Collectively, these provide a foundation for the ensuing chapters.

In section 2, common agendas across aging and disability consumer populations and service networks are evaluated. Elias Cohen and Rosalie Kane each outline ideological, political, programmatic, policy, and consumer issues that generate substantial challenges for cross-network collaborations and coalitions. Elias Cohen provides a strong historical analysis on the evolution of aging and disability policies and what collaborative position that leaves each constituency group in today. Rosalie Kane identifies key organizations, alliances, and issues within the area of long-term care that serve as potential coalition points for aging and disability advocacy communities. They conclude their respective analyses by discussing how and why these might change. Ed Ansello and Mike Oxford draw on their individual experiences in forging partnerships across aging and disability organizations and among older and younger people with disabilities to elucidate the finer points to building, maintaining, and sustaining collaborations and coalitions. Ed Ansello speaks specifically about partnerships across aging and developmental disability service providers and details the importance of involving consumers and families. Mike Oxford recounts successful coalitions built between older and younger consumers with disabilities and professional advocates to address funding and service needs for home and community-based support services. Additionally they each identify determinants of success and points of termination for collaborative and coalition initiatives.

Chapters in section 3 discuss the work of moving partnerships forward through research, evaluation, and policy interventions. Laurie Powers provides a strong argument for the inclusion of persons with disabilities as research partners and from her own experience maps how to successfully conduct participatory action research. Margaret Campbell describes the shift in the federal government toward funding outcome-oriented research, presents a model for making this shift in a research project,
and identifies why this shift is important for improving accountability of results in aging and disability research. Fernando Torres-Gil provides an insightful analysis of the politics that surround the aging-with-disability demographic trend and suggests caregiving concerns as a potential uniting issue for older and younger persons with disabilities. In the concluding chapter, I draw together the thematic threads of the volume and highlight areas of practice, policy, and research that promise to help advance aging and disability cross-network collaborations and coalitions.

This volume of work is important in that it provides analysis and commentary that are intended to move forward practice, policy, and research interventions that facilitate better collaborations and coalitions across aging, developmental disability, and physical disability service networks. It offers a place to start new initiatives (and continue successful ones) in this area by drawing upon the expertise of those who have been building knowledge and engaging in aging and disability partnerships, collaborations, and coalitions for some time. The work of crossing network lines is, and continues to be, challenging. It requires much patience, understanding, and outreach across aging and disability service networks, professionals, and consumers. To the extent that this volume further opens, invigorates, and expands practice, policy, and research dialogues on aging and disability cross-network collaborations and coalitions, we as contributors will consider it a success.

Michelle Putnam
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REFERENCES

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SECTION ONE

Introduction to Cross-Network Collaborations and Coalitions
The chapters in section 1 seek both to introduce the topic of cross-network collaborations and coalitions to the reader and provide a context for understanding the current status of these activities. Central themes across the chapters in this section are (1) the need to understand the historical policy context from which aging and disability service networks emerge, (2) the importance of moving from anecdotal perceptions of what the problems are to an empirically based analysis of the central issues that act as either barriers or facilitators to working across networks, and (3) the significance of including stakeholders in the research dialogue. Together, these themes help to ground the later chapters’ discussions of program and policy change, strategies for working across aging and disability organizations, ways to develop relevant research knowledge in this area, and the politics that influence all of these.
Growing older and having a disability are different experiences. Or at least that’s how individuals, institutions, and public policies have historically posited them. Immediately this statement requires a caveat, however, as aging is often envisioned by most people to include the experience of disability. The converse, that disability will necessarily include the experience of old age, is newer. In the past, many people with significant impairments acquired in youth or middle age did not live as long as their nondisabled counterparts. Thus we are at the forefront of a new trend—aging with long-term disability. This phenomenon, as it is sometimes thought of, is pushing the boundaries of gerontological science through its diversification of the aging population. It also stretches the field of disability studies to include older adults and aging issues within the disability rights mission.

Over the past decade, policy initiatives have begun to target both older adults and people with disabilities under one umbrella, principally for efficiency of administration and service delivery. From a macro perspective, a universal, streamlined means of providing benefits and services can be viewed as an effective programmatic approach, particularly

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A previous version of this chapter entitled “Issues in the Further Integration of Aging and Disabilities Services” appeared in the Public Policy and Aging Report, 14(4), 1, 19–23.
in light of a growing consumer base and limited funding. However, a more micro analysis reveals many difficulties in “merging” aging and disability program consumers and service networks. In large part this is related to the distinct policy histories of aging and disability in the United States. There have been in the past, and currently are, common concerns that people who are aging and who experience disability share in areas including work, health care, family life, and community participation. But their respective thoughts about who they are and what they need in terms of assistance are often not the same.

Before the details of this are discussed any further, a technical note about definitions of disability is warranted to better ground arguments in this chapter and throughout the volume. The phrase “persons with disabilities” includes individuals who have a mental or physical impairment that substantially limits one or more major life activities have a record of such an impairment, or are regarded as having such an impairment. This is the broadest definition of disability in U.S. law and is found in the Americans with Disabilities Act (1990). The definition of developmental disability is more narrowly defined. In general, a person with a developmental disability is considered to have a severe chronic disability attributable to mental or physical impairment (or a combination of both) that is manifested before she or he is 22 years of age and is likely to continue indefinitely. Codification of this definition is found in U.S. Code Title 42, Chapter 144, entitled Developmental Disabilities Assistance and Bill of Rights (2006). Developmental disabilities often result in substantial functional limitation in areas such as self-care, language skills, learning capability, mobility, self-direction, and capacity for independent living. Persons with a diagnosis of physical disabilities, such as spinal cord injury, before age 22 can also be classified as experiencing developmental disability.

Examples of diagnostic conditions that persons aging with developmental disability may have are traumatic brain injury, mental retardation, and autism. Examples of diagnostic conditions persons aging with physical disability may have are polio, spinal cord injury, multiple sclerosis, cerebral palsy, and amputation. Some physical impairments are associated with cognitive and mental impairments but are not identified separately in this volume. These classifications should offer some clarity to this volume’s discussions. However, population definitions must maintain some generality, as unique definitions are found across federal, state, and local policies and programs. Older adults are more clearly categorized as people over 60, 62, or 65, the most common ages of eligibility for federal old-age programs. The complexity of categorizing populations offers some insight into how these population groups are socially constructed.
CONSTRUCTING AGING AND DISABILITY

The difference between aging and disability is not simple. A complex history of cultural ideology, social and economic forces, and policy interventions constructs two distinct realms of age and disability in the United States. This is in spite of what might be seen as intuitive similarities of conditions or circumstances across people with disabilities, regardless of age. Much of the distinction hinges upon views and perceptions of human capability, engagement in paid employment, and the relative age of disability onset. Dating back to colonial society, work, or productive social or economic contribution to a community, has been a national hallmark of individual value and virtue. Adults unable to work due to poor health or limited functional ability who were without other means of economic support were frequently relegated to poorhouses or assigned indoor relief work. These individuals typically occupied positions of relatively low social worth within their communities. Through the period of industrialization, persons of all ages with disabilities continued to comprise the margins of the paid labor force, particularly as immigration in the late 19th and early 20th centuries increased the “healthy” labor force pool. With limited opportunity to secure a living, poverty, and in turn negative social perceptions of people with disabilities, endured. Greater public recognition of the press of economic forces and shifts in the labor market in the late 19th and early 20th centuries helped to generate a stronger impetus for the creation of public policies to address the problems of work and poverty among older adults and people with disabilities. Until this time, national categorical public benefits based on age or disability had been quite limited.

Defining Difference Through Public Policy

The United States government began paying disability-related and old-age pensions to soldiers shortly after the Revolutionary War. War pensions continued to be issued to veterans of the Civil War as well as other military engagements through the 19th century. These represent some of the first federal programs for disability and old age (Skocpol, 1992). As industrialization progressed, the federal government began to widen its scope of interest in disability policy, prompted in part by significant labor policy issues, including worker safety, injury compensation, and unemployment. Thus the 20th century saw the solidification of a disability program set in the United States. At the same time, initiatives to create a national old-age insurance program were also underway. Many states already had their own pension and income supports for older adults. However these were uneven across states, as was the economic burden
to support them. In part, these factors contributed to national calls for a more “universal” old-age retirement policy. Old-age insurance differed from disability compensation in that it insured workers against poverty after they left the labor force, while disability payments compensated an on-the-job loss. Given the shorter age range of work life, it seems likely that in actuality disability—whether attributed to old age or injury or poor health—was a common characteristic of beneficiaries of these policies. However, defining this attribution became more important as life span increased and workplace practices became safer.

As the aforementioned federal policy initiative was under conceptualization, older adults and people with disabilities were working on two separate political agendas. Across the county, but particularly in the northeast, individuals who were blind were actively engaging in discourse with large employers and demonstrating against discriminatory hiring practices. In 1935, a strike against New York City’s Emergency Relief Bureau protesting employment discrimination by what would soon be known as the League of the Physically Handicapped was one of the first organized political action events by persons identifying as disabled (Longmore & Goldberger, 1997). In similar fashion, other disability-related organizations, including disease-specific affinity groups, lobbied for greater recognition and better treatment of their constituencies. Many times these groups were led by persons without disabilities, but often they included people with disabilities in their leadership. Older adults and their representatives were also active politically in issues of poverty, housing, and age-based discrimination during this time period. Even at this early juncture, however, segmented political agendas often related back to the perception of disability as a normative part of growing old, and an abnormal part of being young or middle-aged. People with developmental disabilities were less active politically in the early 20th century. In general, children who were born with or acquired developmental disabilities before adulthood were institutionalized or otherwise kept out of mainstream public venues. Limited advocacy existed on their behalf.

The advancement of medicine is intertwined with these political and policy contexts. Knowledge development in basic medical practices and technology, disease management, surgical procedures, and rehabilitation helped to medicalize the social constructions of aging and disability. Viewing both phenomena through a “curative” lens formally allowed the medical field to diagnose the “abnormalities” of disability and the “problems” of aging. Neither of these perspectives was particularly new. From a federal policy perspective, disability and old age put individuals “at risk” for poor health and economic hardship. Policy goals were aimed at reducing these risks. Additionally, the eugenics movements of the early 20th century and the long-standing cultural disparagements of
old age as a time of physical decrepitude shaped both social and scientific assumptions. This mix of social, economic, political, and scientific factors drew parallels between aging and disability while at the same time distinguishing them as different phenomena. From the 1950s to the 1970s, assumptions of aging and disability became further codified through social welfare programs and policies. For example, the Older American’s Act, Medicare, Medicaid, Supplemental Security Insurance, and amendments to Social Security’s Old Age Survivor’s Insurance program all significantly benefited older adults while reinforcing social perceptions of vulnerability in old age. Social Security Disability Insurance through its qualification procedures formalized disability as an equation of medical prognosis, and employment potential further grounded disability’s definition in economic terms. While these policy strides were great and offered relief to many, the political context of the policy discussion for people with disabilities was beginning to change.

Civil Rights and the De-Medicalization of Disability

In the late 1960s and early 1970s, service networks for people with disabilities and older adults were becoming more formalized through federal funding. During this period, the synergy of civil rights movements, greater numbers of people with disabilities attending college, and significant skilled leadership by people with disabilities spurred the launch of the independent living movement (Scotch, 1989). The independent living movement argues for the granting of full citizenship rights to people with disabilities, including access to social, economic, and political opportunities and resources and inclusion in mainstream society. It is premised on a sociopolitical model of disability as opposed to a medical one. The sociopolitical framework posits disability as a resultant interaction of a person within a particular environment (Hahn, 1994). In its simplest terms, disability is an outcome, not an individual trait. Disability occurs when there is a mismatch of personal ability and environmental characteristics. These characteristics include both physical factors and social attitudes that together create inaccessible environments for people experiencing disability. The disability equation can be modified either through processes such as rehabilitation, which may modify a person’s ability, or an increase in an environment’s accessibility and accommodation. When the person and the environment are well matched, disability does not exist. Using this framework, independent living is defined as a state in which one is able to achieve one’s daily goals with or without accommodations or assistance. Full citizenship implies the right to live in communities where physical, social, and cultural barriers to community participation and civic engagement for people
with disabilities are no more cumbersome than those for people without disabilities. Additionally, individuals with disabilities assume the right to self-determination.

Several landmark disability laws have been passed in the last three decades. The independent living movement marked one of its first broad-based legislative victories for disability rights with the passage of the Rehabilitation Act of 1973. Included in this bill was a demonstration project, community-based Centers for Independent Living (CILs). CILs were charged with offering information and referral, peer support, and independent living and self-advocacy education and training to people of all ages with disabilities. The Rehabilitation Act has been continuously reauthorized, and CILs has become a permanent program. The Education for All Handicapped Children Act, passed in 1975 and later renamed the Individuals with Disabilities Education Act, signified political progress for persons with developmental disabilities and their families. This bill provided the right for equal access to public education for persons with developmental and intellectual disabilities. The signal legislative achievement of the disability rights movement to date is the signing of the Americans with Disabilities Act (ADA) into law in 1990. The ADA is the first dedicated, broad-based civil rights legislation for people with disabilities in the United States. Collectively, these policies have helped to institutionalize the sociopolitical model of disability and re-shape disability-related programs and services. This shift and the civil rights movement that helped launch it, however, have occurred for the most part without significant participation or input from older adults as a constituency of the population experiencing disability.

The Growing “Voice” of Disability

The independent living movement originated, like other movements of the time, as a youth-based movement. Key issues included accessibility and accountability. People with disabilities wanted to stop being patronized and considered as “lesser” than people without disabilities. Theirs was not a situation to be pitied, but one to be analyzed within a political context that sought to identify who and what was fostering ideals, environments, and policies that limited their full participation and inclusion in society. Thus fighting to “de-medicalize” disability was essential to redefining a problem that was not about human inability but about lack of social, economic, and political opportunity. Marginalization and lack of authentic voice were crucial contributors to that problem.

As disability rights activists took up their battles, issues related to aging or old age were largely peripheral. Solidarity from old-age activist groups was limited. On a global level, the issues that disability and aging advocates championed overlapped at that time—poverty, housing, employment
discrimination, transportation, access to quality health care, personal assistance, and caregiving services. However the perceptions of disability within each group were largely different due in part to each individual’s unique indoctrination into the disability experience and the age at which impairment occurred. Disability first encountered in youth or early adulthood may affect opportunities for engagement in normative life-course activities like education, work, family life, and social and civic participation. Disability acquired for the first time in old age shapes only that phase of life. Thus from a physiological perspective, there may be a similarity of physical experience of disability across ages, but from a sociological perspective, factors ranging from discriminatory attitudes and behaviors that limit access to education, social interactions, employment, and family life to economic marginalization due to high costs of health care, limited career opportunities, and duration of disability all are significant variants. These differences in the experience of disability help draw distinctions by age.

As disability rights and aging-related political advocacy groups continue their work today, disabilities in young and old age continue to be viewed as separate concerns. Old age is commonly identified by both aging and disability advocacy groups with slowing down, retiring, pursuing leisure activities, and often ill health and frailty. Disability is typically identified with poor health as well, but also concerns about employment and social inclusion. From a disability rights perspective, the fundamental challenges for younger adults with disabilities are viewed as different from those faced by older adults with disabilities. From an aging advocacy standpoint, older adults are in a different life stage than younger adults and need different supports and services. In sum, older and younger adults with disabilities are viewed as advocating from different positions related to chronological age. Advocacy strategies underlie this point as disability rights groups prioritize advocacy by people with disabilities themselves, and older adults are often represented by much younger, and often professional, advocates. Thus the paths of disability and aging advocacy from the beginning of the 20th century until the present day are much their own. Until now, this lack of political integration has been a limited concern. However, the demographic trend of aging with disability and the policy movement toward the institutionalization of independent living principles are highlighting the current and future challenges this historical separation creates.

AGING WITH DISABILITY AND THE INCREASED DIVERSIFICATION OF THE AGING POPULATION

Advances in medical science, public health, and public policies over the last century have created greater accessibility, opportunity, and support
AGING AND DISABILITY

for people with disabilities. These have contributed to the recently identified phenomenon of aging with disability. “Aging with disability” refers to the trend of people who were born with or acquired substantial developmental or physical impairments in early- or mid-life living into old age. Although statistics on the population of middle-aged and older adults who are aging with disability are limited, it is estimated there are several million individuals who currently comprise this population, and it is believed to be growing (Torres-Gil & Putnam, 2004). This growth trend is occurring at the same time disability incidence is reported to be declining in the over-65 population in general, although there remains high prevalence at age 80 and above (Crimmins, 2004). Thus it may be fair to say that while older adults on average appear to be experiencing less disability, with the infusion of the aging-with-disability population, the types of disability-related conditions and impairments among the older adult population will broaden. Almost by default then, the experiences of disability that people bring with them into old age will create a more heterogeneous older population.

The aging-with-disability phenomenon brings into sharp focus the lack of integration between scholarship in the fields of gerontology and disability studies and the resultant limited understanding of how the experience of living long-term with disability influences the experience of aging. Additionally it raises new questions about the direction of future scholarship, research, and practice. Although there are no clear predictions for life expectancy among individuals aging with substantial disabilities, there is some evidence that it is different from that of persons not aging with disability and that these differences are important. In the area of physical health alone, issues related to “accelerated” aging, secondary conditions (new declines in health and function that occur after the onset of the primary disability and are either directly or indirectly related to the underlying impairment), and diagnostic specific post-onset syndromes are signaling added complications in old age that were unanticipated by clinicians and their patients. Medical science is only beginning to understand the biology and physiology of aging with disability. Knowledge within social science disciplines is equally limited. There is much work to be done to “catch up” with the aging-with-disability trend in the areas of scholarship, professional practice, and consumer knowledge building. This statement implies that across the board, work in this area is behind. This is in fact true in that aging with disability is a demonstrable trend, people aging with disabilities are encountering problems and issues related to it, and these are seen by professionals within aging and disability service systems, who are incurring difficulties in addressing cross-population needs and in working across service networks.
THE MOVEMENT TOWARD INSTITUTIONALIZING INDEPENDENT LIVING PHILOSOPHY

The trend toward greater consumer control and self-direction of support service provision is in large part attributable to the independent living movement and has in the last decade begun to gather significant steam. Centers for Independent Living were perhaps the first organized implementation of the independent living model. However, more wide-based acceptance was signaled by the incorporation of its principles into a Medicaid demonstration project for home and community-based services started in the late 1990s and titled the Cash and Counseling program. Funded jointly by the Robert Wood Johnson Foundation and the Department of Health and Senior Services’ Office of Long-Term Care Policy and Planning, the original three-state demonstration in Arkansas, New Jersey, and Florida has now been extended to additional states and is yielding evidence that consumer direction can be a viable service delivery mechanism.

Even as results of this demonstration continue to be compiled, independent living principles are becoming more significantly anchored in public policy. Of particular weight is the 1999 Supreme Court ruling in Olmstead v. LC mandating that individuals with disabilities must be provided services in the most community-integrated setting possible in order to comply with the ADA. The New Freedom Initiative, which followed in 2001 as an executive order charging all federal entities and organizations that receive federal funds to comply with the Olmstead ruling, sank the disability rights agenda even deeper into national policy. Part of this initiative, which directly affects persons aging with disabilities, is the creation of Aging and Disability Resource Centers (ADRCs). These are state-based program demonstrations jointly supported by the Centers for Medicare and Medicaid Services and the Administration on Aging. ADRCs are designed to serve as “one-stop shops” for older adults and people with disabilities seeking community resource and support service information.

As these policies and programs move forward, they are beginning to create greater mainstream acceptance of what was once viewed as radical ideology and a few side trends of particular note. First, they are generating questions about the role of and need for “professional” case management among consumers and professionals alike. With the introduction of choice and flexibility, segments of both the older and younger consumer populations see case management as an outdated model of service delivery. In response, professionals are questioning the viability of consumer-directed models for all consumers and seek greater clarification and often regulation of service delivery for the purpose of...
ensuring safety and quality of services as well as reducing fraud. Many aging and disability advocacy organizations are requesting flexibility in program design to accommodate varying needs of people with cognitive impairments like dementia, individuals without extensive social support such as aging adults with developmental disabilities, and those for whom traditional models are less well suited, such as persons living in remote rural areas. Second, they are forcing consumers to move outside their traditional service network structure, such as in the case of older adults enrolling in independent living programs administered by state vocational rehabilitation or people with disabilities receiving services from traditional aging-service providers, like area agencies on aging, which are granted “disability” funds to augment transportation services to younger adults with disabilities. This crossover of consumer populations often challenges professionals working within aging and disability service networks to meet the needs and address the concerns of individuals they are less familiar with and sometimes less prepared or able to assist.

In short, the population trend of aging with disability, combined with the policy shift that is beginning to embrace the independent living philosophy, is reshaping aging and disability service networks. As this happens, professionals working within these networks are charged with addressing the diversifying population needs and implementing policy and program initiatives. Thus the groundwork of service delivery is changing, and so too are the activities of service network professionals.

CROSSING AGING AND DISABILITY SERVICE NETWORK LINES

Federal, state, and local policies governing service provision to older adults, people with developmental disabilities, and people with physical disabilities essentially divide into three “service systems.” Aging and disability service systems are generally loosely formed networks that both intentionally and unintentionally link organizations and agencies that administer and deliver services to older adults and people with disabilities. Receipt of services is usually determined by eligibility criteria related to age or disability. Depending on the type of services provided and the eligibility criteria required to receive them, some organizations may have mostly older adult consumers, while others serve primarily younger people with disabilities, and there are those that provide services to both. Moreover, within each network, the mission and activities of organizations differ. Some are involved primarily in direct provision of services and other administrative management, including contracting with other service providers. Organizations may also be primarily focused
on consumer advocacy and involved very little in the administration of programs or direct delivery of services.

The organizations that comprise each service network are both public and quasi-public; some receive funding only from government sources, and others are supported through a mix of private and government funds. Sometimes network organizations are in competition with each other, but there are many that provide complementary services and do not necessarily see themselves as in the same market. The perception of which network an organization belongs to is often determined subjectively by the types of consumers they primarily serve (e.g., older adults, persons with developmental disabilities, and individuals with physical disabilities), or more objectively, based on where their primary source of funding comes from (e.g., earmarked government funds for a certain population) and what the mission statement of the organization is. Aging, developmental disability, and physical disability service networks can be outlined based on analysis of these traits, although there are many organizations that may play a role in multiple networks.

Arguably, there has always been overlap among aging and disability service network consumer populations as eligibility for programs and services have varied and structures of networks have changed over time. Additionally, some would legitimately debate the extent to which each set of programs creates a definable service system or a service network, given that there is no mandate for agencies and organizations to position themselves into a discernable and logical structure. It may be more the forces of social will and market economies that create the connections and voids often seen between service providers and organizations. However, the term “service network” is useful for attempting to describe and understand the collection of organizations and agencies that provide services to older adults and people with disabilities. It may be critiqued as a term of convenience, but it is helpful in mapping out the range of services available and the normative consumers of those services.

From the consumer perspective, a service network can be thought of as a set of organizations whose programs offer services for which an individual is eligible based on a particular characteristic (e.g., age or disability status). From the practice professional’s viewpoint, there are organizations and agencies that serve similar populations and whose programs and services are complementary or in competition. From the policy maker’s standpoint, there are political constituencies who argue for distinct policies, programs, and funding formulas, and these are provided to them through a set of administrative structures and mechanisms that can be viewed in terms of a network. Service networks are perhaps a broad vehicle to connect together government funding, but when lawmakers are held accountable for supports to a particular population, all funded
programs based on eligibility category may be pulled into the mix for evaluation. Viewed from these positions collectively, it can be said that different service networks are perceived and, in fact, do exist—even if they are hard to categorize and quantify.

Most aging and disability service networks are somewhat unique with variation created through regional mixtures of federal, state, and local funding, program, and policy initiatives. For this reason, it is hard to identify a universal network structure or definitive network boundaries. However, figure 1.1 attempts to provide a general conceptualization of aging and disability service networks by presenting a list of commonly shared service interests among older adults, people with physical disabilities, and individuals with developmental disabilities as well as the common organizational players found within and across aging and disability networks.

Historically, organizations within the three service networks have occasionally interacted and partnered at the local, state, and federal levels when common concerns or agendas exist. However, there have been limited long-standing collaborations or coalitions due to their historically different programs, policies, and consumers. The result has been some mutual recognition among players in these three networks, but limited opportunity to develop knowledge and understanding of each other.

FIGURE 1.1 Common organizational players and shared consumer interests found within aging and disability service networks.
While this might now be viewed as a loss, for the most part it was not often identified as a critical problem. The importance of working more closely together is beginning to be more widely recognized. As both eligibility categories and programmatic ideological underpinnings begin to blur, macro policy initiatives and their micro implementation issues hinge on bridging historical network lines. Given their separate political and policy pasts, building and sustaining these bridges is not a simple task. In the next chapter, barriers to and facilitators of cross-network collaborations and coalitions are explored in depth with the goal of understanding how to address the difficulties professional service providers encounter in working across aging and disability service networks.

REFERENCES


