
Long-Term Care for the Younger Population: A Policy Synthesis

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Although long-term care financing issues for older adults has been a public policy issue for 3 decades, long-term care for younger people has been virtually ignored until recently. This paper looks at the size of the younger population, what younger people want from the long-term care system, how service delivery should be organized, and what options are needed to finance services for younger people with disabilities.

Although attention to the problems in the long-term care system for older adults has increased, similar problems facing younger people with disabilities have been ignored by policymakers until recently. Between one third and two thirds of all disabled people are not elderly, but little is known about how younger people finance and use long-term care.

Interest in younger people with disabilities has grown for two reasons. First, younger people with disabilities have demanded recognition. After the 1990 enactment of the Americans With Disabilities Act, younger people made long-term care reform a priority and pushed themselves into the political process. Second, advocacy groups for older Americans have promoted long-term care as a problem affecting all ages to counter arguments that public long-term care spending takes money away from younger people.

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Disabled People Under Age 65

The size of the population of younger people with disabilities is fundamental to policymaking, but has conflicting implications. If the number is large, more public attention is needed. But the bigger the population, the larger the expense and the less willing public officials may be to commit resources.

Estimates Vary Substantially

In 1995, the estimated number of young people with disabilities living in the community varied from 20 million to 33 million, with between 1 million and 14 million having substantial disabilities. Depending on estimates, younger people with disabilities account for one third to three quarters of those with disabilities living in the community. Also, recent statistics indicate that about 1 million people under age 65 with disabilities are homeless, in jail, or in institutions such as nursing homes or long-term care facilities.

Philosophy Behind the Disability Movement

One major impact from the disability movement has been a rethinking of the goals for long-term care, which in the past had been limited to keeping older people safe, clean, and well fed. Advocates for younger people reject these goals, arguing that they are far too limited. This group believes that the aims of long-term care should be to maximize independence and self-sufficiency (DeJong, 1979), implying a radical change in how the services should be organized and financed (Simon-Rusinowitz & Hofland, 1993). This philosophy has five basic tenets:

- Younger persons with disabilities reject the notion that a disability makes them less of a person. They argue that people with disabilities are handicapped by society's attitudes and barriers in the environment, not by their impairment (DeJong, 1993). According to this view, the service system's goals should be to provide access to the same freedoms associated with full community integration, including working at paying jobs, marrying and having a family, and realizing their potential as human beings.
- Disabled people are capable of making decisions about their lives. For people with mental retardation and mental illness, the scope of decision making is usually expanded to family and friends, although not always. Advocates of this philosophy oppose medical models that include professional case management and institutionalized care.
- Because each person is unique, the philosophy suggests that services should be tailored to the individual needs and desires of each person with a disability. Advocates of this idea reject traditional goals of long-term care for older adults that offer a continuum of personal care, home health, and nursing home care, which individuals progress through as their disability increases. Instead, they believe services should follow individuals and should be provided regardless of where individuals live.
- Services should be a right, not the result of charity, because each individual is capable of a normal life in the community. In contrast with older adults, unpaid and informal care from family and friends is considered undesirable because it leaves people with disabilities vulnerable to the whims of their caregivers.
- To replace the existing system, advocates propose a more unified financing system that would provide a broader range of ways for people to finance their personal needs. According to this view, the system should emphasize individuals' needs for personal assistance, not their finances.

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Delivery System Organization

Although the use of institutions by younger people with disabilities is declining, this type of care still plays a role in the delivery of long-term care, especially for those with developmental disabilities. For people living at home, the existing system relies heavily on informal care. In 1986, family members provided care to 87% of nonelderly individuals who were living in the community and needed help with personal care, getting around the house, preparing meals, or managing their money (Harpine, McNeil, & Lamas, 1990). Recent statistics indicate that paid services account for a small but significant share of home care. Of the nearly 6 million users of formal home care in 1987, about half were under age 65 (Altman & Walden, 1993).

Replacing Institutional Care

A strong dividing line between younger and older persons with disabilities involves the role of institutions in long-term care. Advocates for younger people see institutions as the antithesis of everything the system should be—little personal autonomy and independence, community segregation, professional domination, and standardized instead of individualized services (Shapiro, 1990, 1991). In contrast, although older adults seek to avoid nursing home placement, there is more acceptance of the major role of institutions for older people, especially those without family support (Rivlin & Wiener, 1988).

A key question of policymakers is whether advocates' goals of radically reducing institutions and replacing them with home and community-based care is practical and affordable (Smith & Gettings, 1994). Almost everyone could be served in the community if enough resources were available. However, questions remain regarding how much it costs to do so for people with very involved disabilities, particularly those with cognitive impairment. Some have argued that providing home and community services to severely disabled older adults could exceed the cost of nursing home care, especially if people do not have strong informal supports. However, intermediate care facilities for the mentally retarded are so costly that community-based services are often less expensive per person. The cost of intermediate care facilities averaged \$62,180 a year in 1993, whereas the cost per person under the Medicaid home and community-based waiver program was \$25,176 (Mangan et al., 1994).

An issue complicating per-person costs is the “woodwork effect.” Specifically, an increased number of people might come out of the woodwork to use a broad range of community-based services if they become available. Studies show that in demonstration projects offering expanded home care to older adults, total costs rose rather than declined (Wiener & Hanley, 1992).

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Flexibility and Scope of Services

A significant issue related to the consumer movement among people with disabilities relates to the responsibility taxpayers have to disabled people. Is the public's responsibility only to help people meet certain basic, minimal needs, or is it to truly help people with disabilities realize their potential and live full lives?

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A major issue for younger people with disabilities is the extent to which the existing long-term care system can be adapted to encourage greater workforce participation. Although less than a quarter of younger adults with disabilities are employed, most unemployed disabled adults say they would like to work (Harris & Associates, 1994). Advocates point to real jobs, rather than sheltered workshops that pay minimal wages, as the key to financial independence for disabled adults.

Managed Care

As with older adults, there is increasing interest in integrating acute and long-term care services for young people, mainly through the use of HMOs and other managed care (Wiener & Skaggs, 1995). A concern among advocates, however, is that long-term care would become overmedicalized and less consumer-directed in integrated settings.

Personal Assistance Services

Advocates of consumer-directed services argue that people who use services should be in direct control of service delivery, including the hiring, training, supervision, direction, and firing of attendants. By definition, the worker would do what the client wants. This raises several issues, including whether disabled people are capable of performing these functions; whether everyone with disabilities wants to manage their own services; what the quality assurance of care would be; and whether the market would provide enough qualified workers, especially because studies have found most independent personal care workers are employed at just above the federal minimum wage.

Long-Term Care Financing

Long-term care services for younger people with disabilities are financed through many sources, including a large number of public programs at the state and federal level, out-of-pocket payments, and private insurance. Overall, spending has been viewed as inadequate by advocates and is mostly limited to institutions and a narrow set of home and community services. The reliance on Medicaid excludes many people who are not poor but who cannot afford to pay for out-of-pocket services. Strong work disincentives are tied to Medicaid in efforts to limit eligibility to people who cannot work. Furthermore, private long-term care insurance, which holds some promise for older adults, seems unlikely to work for younger people.

Public Financing Sources

Medicaid spent \$44 billion on long-term care in 1993, not including mental health services. Of that amount, 38% was for nonelderly services. Medicaid accounts for a significantly larger proportion of long-term care financing for younger people than for older adults with disabilities. Medicaid is an especially important

funding source for institutional long-term care, although it also plays an important role in noninstitutional long-term care services for younger people with disabilities. Total Medicaid expenses for noninstitutional long-term care in 1993 were \$7.4 billion, of which nearly half went to younger people (Office of Assistant Secretary for Planning and Evaluation, 1994).

People with disabilities who receive Social Security Disability Insurance (SSDI) for 24 months are eligible for Medicare. Medicare plays a modest role in long-term care financing. In 1993, it paid approximately 20% of nursing home and home care expenses for older adults, and only 3% of the expenses for younger disabled people (Wiener, Illston, & Hanley, 1994).

State funding accounts for much more long-term care spending for younger people, compared with the elderly. Not including Medicaid matching payments, the states contributed 20% of the total long-term care expenditures for the nonelderly in 1993, compared with just 1% for older adults.

Policy Issues

The existing long-term care financing system for younger individuals raises at least five major issues. First, financing and services for younger people with disabilities is mostly available for institutional, rather than community-based, services. Second, conflict exists between open-ended entitlement programs, such as Medicaid, and government spending on a very broad range of services with capped funding and no entitlement. Third, eligibility rules for Medicaid and Medicare encourage dependence, not independence. To qualify for Medicaid or Medicare with a disability, applicants must meet eligibility requirements based on inability to work. This presents disabled people with a difficult dilemma. They can work and lose income, health care, and long-term care coverage, or they can remain unemployed and receive benefits, but give up the opportunity for financial and personal independence.

Fourth, important sources of long-term care financing are means tested, which often results in lower political support, stigma among beneficiaries, and inferior access to services that are sometimes of lesser quality (Wiener et al., 1994). Finally, resistance to the expansion of public programs means there is increasing interest in private long-term care insurance as a means of financing services for older adults. Unfortunately, its role in financing long-term care is limited by problems of affordability and marketability. In addition, private policies do not seem to be of interest to younger people with disabilities. More importantly, because all individually sold policies are medically underwritten, members of the younger disabled population tend to be excluded from purchasing such policies in the first place.

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Concluding Remarks

This synthesis of research and policy issues and research indicates that to adequately meet the needs of younger individuals with disabilities, policymakers will need to reconsider the goals of long-term care, address issues related to service delivery, and develop creative mechanisms for financing services. Recent research indicates that younger disabled individuals comprise an increasingly important force in the policy arena. As such, any future policy initiatives in long-term care will almost certainly need to consider the younger as well as the older disabled population.

References

- Altman, B. M., & Walden, D. C. (1993). *Home health care: Use, expenditures, and sources of payment*. Rockville, MD: Agency for Health Care Policy and Research.
- Americans With Disabilities Act of 1990, Pub. L. No. 101-336 (1991).
- DeJong, G. (1979). Independent living: From social movement to analytic paradigm. *Archives of Physical Medicine and Rehabilitation*, *60*, 435–436.
- DeJong, G. (1993). Independent living. *Policy Studies Journal*, *21*, 724–734.
- Harpine, C. J., McNeil, J. M., & Lamas, E. J. (1990). The need for personal assistance with everyday activities: Recipients and caregivers. *Current Population Reports, Household Economic Studies, P-70*, 19.
- Harris, L., & Associates. (1994). *National survey of Americans with disabilities, Harris survey of Americans with disabilities*. Washington.
- Mangan et al. (1994). *Residential services for persons with mental retardation and related conditions: Status and trends through 1993*. Minneapolis, MN: University of Minnesota.
- Office of Assistant Secretary for Planning and Evaluation, Office of Disability, Aging, and Long-Term Care Policy. (1994). *Cost estimates for the long term care provisions of the Health Security Act*. Washington DC: Department of Health and Human Services.
- Rivlin, A. M., & Wiener, J. M., with Hanley, R. J., & Spence, D. A. (1988). *Caring for the disabled elderly: Who will pay?* Washington DC: Brookings.
- Shapiro, J. P. (1990, April 15). A life worse than death. *Washington Post*, p. D1.
- Shapiro, J. P. (1991). Forcing the young into nursing homes. *APF Reporter*, *14*, 11–15.
- Simon-Rusinowitz, L., & Hofland, B. F. (1993). Adopting a disability approach to home care services for older adults. *Gerontologist*, *33*, 159–167.
- Smith, G. A., & Gettings, R. M. (1994). *The HCB waiver and CSLA programs: An update on Medicaid's role in supporting people with developmental disabilities in the community*. Alexandria, VA: National Association of State Directors of Developmental Disabilities Services.

- Wiener, J. M., & Hanley, R. J. (1992). Caring for the disabled elderly: There's no place like home. In S. M. Shortell & U. E. Reinhardt (Eds.), *Improving health policy and management: Nine critical research issues for the 1990s* (pp. 75–110). Ann Arbor, MI: Health Administration Press.
- Wiener, J. M., Illston, L. H., & Hanley, R. J. (1994). *Sharing the burden: Strategies for the public and private long-term care insurance*. Washington, DC: Brookings.
- Wiener, J. M., & Skaggs, J. (1995) *The integration of acute and long-term care financing and services: A policy synthesis*. Washington, DC: American Association of Retired Persons.