

Livable Communities for Adults with Disabilities

In 2004, the National Council on Disability (NCD) commissioned the Center for Home Care Policy and Research to research and prepare a report on the topic of “livable communities” for adults with disabilities. The following is a summary of the major findings in the report and the priority action steps that communities should take to become more livable for people with disabilities. The report was published by the National Council on Disability in December 2004. The National Council on Disability is an independent federal agency making recommendations to the President and Congress to enhance the quality of life for all Americans with disabilities and their families. The full report, entitled *Livable Communities for Adults with Disabilities*, includes numerous examples of communities that have made improvements in their livability for people with disabilities. It is available on the Council's website, www.ncd.gov.

Introduction

Communities in the United States are faced with increasingly difficult decisions about how to plan for change and increase and improve the quality of life for adults with disabilities as well as elders who may develop disabilities as they grow older. People are living longer lives today than ever before and the population of people aged 65 and older is growing rapidly. By 2030, one in five people in the United States will be over the age of 65. Currently, more than 4.7 million Americans aged 65 years or older have a sensory disability involving sight or hearing, and more than 6.7 million have difficulty going outside the home. As the population of elders grows, it is likely that the number of people aged 65 and older with disabilities also will grow, particularly among those 75 years of age and older.

Adults with disabilities and elders want to live in their own homes as independently as possible for as long as possible. They want to live in supportive communities that encour-

age independence and a high quality of life. To facilitate independence, they often need the same kinds of services. In addition, they want to remain contributing members of the community. It makes sense, therefore, for the disability community and aging network—groups that traditionally work separately—to collaborate, align goals, and share resources to address the challenges and opportunities ahead.

As the demographic profile of the United States changes, there will be an increased need for livable communities that support the needs and aspirations of people with disabilities and older adults. To meet this demand, three factors must be considered: (1) the elements of a livable community; (2) existing examples of livable communities in the United States today that can serve as models for others; and (3) how these communities develop and sustain livability features.

Framework of a Livable Community for Adults with Disabilities

“Livable community” is a fluid term whose definition may change depending on the context and such considerations as community capacity, organizational goals, and the needs and desires of particular groups of citizens. For the NCD report, a Framework of a Livable Community for Adults with Disabilities was constructed to define the elements that need to be in place for a community to be considered livable for people with disabilities. It is clear, however, that the elements that make a community livable for people with disabilities make it a livable place for all members of the community. Thus, in improving its livability for one particular group of constituents, the community actually accomplishes considerably more.

The Framework of a Livable Community for Adults with Disabilities (Figure 1) is inspired, in part, by a similar framework developed for the AdvantAge Initiative, a project that helps communities measure and improve their

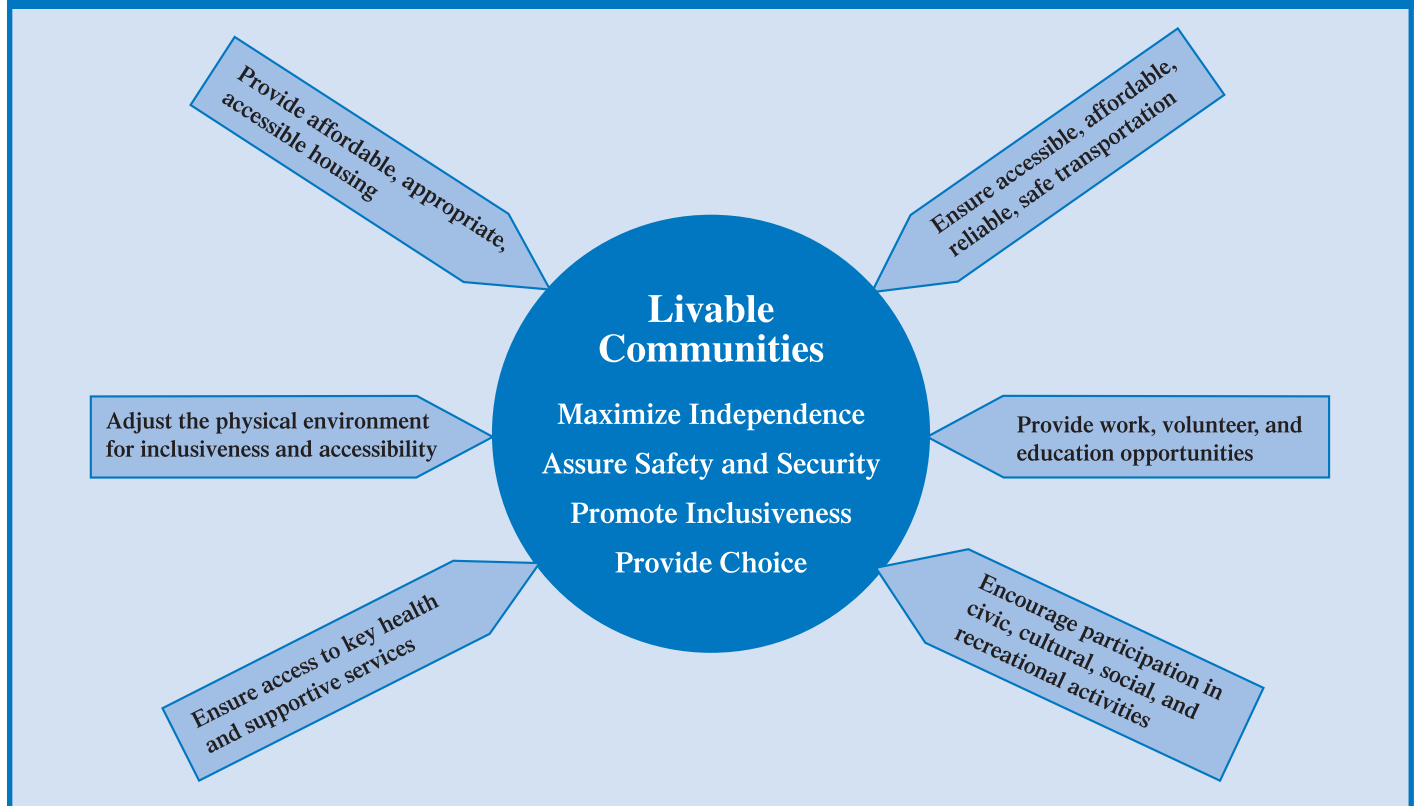
“elder-friendliness.”¹ It was informed further by research on the concept of livability, results of recent surveys of people with disabilities, countless interviews with key informants and people with disabilities, and a focus group session involving people with disabilities aged 30 and older in Washington, D.C. Similar themes emerged from each of these activities and were synthesized into the framework. Thus, a Livable Community for Adults with Disabilities is defined as one that achieves the following:

- Provides affordable, appropriate, accessible housing
- Ensures accessible, affordable, reliable, safe transportation
- Adjusts the physical environment for inclusiveness and accessibility
- Provides work, volunteer, and education opportunities
- Ensures access to key health and supportive services
- Encourages participation in civic, cultural, social, and recreational activities

Within each of these six areas, a livable community strives to maximize people’s independence, assure safety and security, promote inclusiveness, and provide choice.

¹ AdvantAge Initiative Web site at www.advantageinitiative.org.

FIGURE 1: THE FRAMEWORK OF A LIVABLE COMMUNITY FOR ADULTS WITH DISABILITIES



While no one community in the United States has addressed all six of these livability goals to equal degrees, many states, counties, and local communities have made extraordinary improvements in their livability for people with disabilities in one or even several of these areas. Their experiences and achievements can serve as inspiration and provide replicable “best practices,” which other communities can emulate as they strive to become more livable.

Strategies and Policy Levers

Community efforts profiled in the Livable Communities report have employed a variety of strategies and policy levers to: (1) expand access to affordable housing, transportation, and employment opportunities; (2) make the built environment more accessible; (3) reconfigure health and support service delivery systems to be more in line with the needs of people with disabilities; and (4) promote the social and civic engagement of these communities.

Nearly every initiative included in the report has depended, to one degree or another, on strategic partnerships that have worked together to achieve the following goals: (1) leverage resources, (2) reduce fragmentation in the service delivery system, (3) address consumers’ needs in a coordinated and comprehensive manner, (4) provide choice, and (5) implement policies and programs that help people remain independent and involved in community life. To maximize the potential for success, communities should use one or more of the following strategies and policy levers as well as develop all-important partnerships. These strategies and policy levers can and should be used at every level of government—including federal, state, county, and local—to effect change in any of the areas included in the Framework of a Livable Community for Adults with Disabilities:

- Consolidate administration and pool funds of multiple programs to improve ease of access to, and information about, benefits and programs for consumers. This strategy is used to streamline operations, eliminate redundancies, and leverage resources.
- Use tax credits and other incentives to stimulate change in individual and corporate behavior and encourage investment in livable community objectives. This strat-

egy is often used to stimulate affordable housing development, reduce tax burden on individuals, urge employers to hire people with disabilities, and encourage the private sector to make their businesses more accessible to elders and people with disabilities.

- Provide a waiver or other authority to help communities blend resources from multiple public funding streams to provide and coordinate different services. This is a common policy lever in the provision of coordinated health care and support services, allowing agencies to blend funding streams, increase the availability of home- and community-based services as an alternative to institutional care, and support comprehensive and consumer-directed care.
- Require or encourage a private sector match to leverage public funding and stimulate public-private sector partnerships. Several of the community initiatives profiled in the report depend on monetary or in-kind contributions from the private and nonprofit sectors for their continued existence.

In addition to these strategies and policy levers, successful community initiatives often depend on the ingenuity and persistence of community members who are able to mobilize resources, generate excitement, and stimulate action in their communities on behalf of people with disabilities and the elderly.

Lessons Learned and Recommendations

A number of lessons can be gleaned from the community initiatives described in the report, many of which can serve as recommendations to other communities that are planning to make greater livability a priority issue in their locales.

Provide affordable, appropriate, accessible housing

People with disabilities, including the focus group participants, say that satisfaction with housing arrangements is the determining factor for remaining in or moving from their communities, and this satisfaction depends on two key factors: housing affordability and accessibility. “With stable

housing, people with disabilities are able to achieve other important life goals, including education, job training, and employment.”² According to the Public Policy Collaboration, however, people with disabilities “face a crisis in the availability of decent, safe, affordable, and accessible housing,”³ and those with low incomes are the most likely to be affected by this shortage. One estimate says that as many as 1.8 million people with disabilities who receive Supplemental Security Income (SSI) benefits have severe housing problems.⁴

Model community efforts that have expanded homeownership and rental housing options for people with disabilities, have developed strong partnerships and collaborations between the affordable housing system and the disability community. These relationships ensure that the housing created will meet the needs and preferences of people with disabilities and/or elders. Additional priority action steps in the area of housing include the following: (1) providing incentives for developers to maintain existing affordable housing units and/or increase such stock; (2) providing tax credits to help individuals with disabilities and seniors remain in the homes where they currently live; and (3) expanding awareness and encouraging incorporation of universal design and accessibility features into existing or new housing stock.

Ensure accessible, affordable, reliable, safe transportation

According to the 2003 National Transportation Availability and Use Survey, about one in four individuals with disabilities needs help from another person and/or assistive equipment, such as a cane, walker, or wheelchair, to travel outside the home. Nearly 6 million people with disabilities have difficulty getting the trans-

portation they need, because public transportation in the area is limited or nonexistent, they don't have a car, their disability makes transportation difficult to use, or no one is available to assist them. The survey also found that more than 3.5 million people in the United States never leave their homes, and more than half of the homebound are people with disabilities. Of these, more than half a million indicate that, because of transportation difficulties, they never leave home.⁵

Providing accessible, affordable, reliable, and safe transportation is an enormous challenge to communities. To address this challenge, some states and counties have been thinking systemically. Priority action steps in the area of transportation include the following: (1) creating “coordinated transportation systems” that combine all the disparate transportation services and funding streams into one system that is more efficient, cost-effective, and universally accessible; (2) computerizing and centralizing dispatch systems to make on-demand transportation more efficient and less frustrating for consumers; and (3) exploring the use of new technology to help people with disabilities and the elderly navigate their community’s thoroughfares and transportation options.

Adjust the physical environment for inclusiveness and accessibility

Since the passage of the Americans with Disabilities Act (ADA), noticeable accommodations have been made in communities large and small to improve access for people with disabilities. In most communities, however, expanding access to the physical environment is still a work in progress. One of the greatest obstacles to improving access for people with disabilities is the expense associated with altering the built environment and making other needed accommodations. In addition to cost, in larger cities or towns, the sheer volume of work to be done causes delays in making necessary changes. In older communities where there are many historic structures that need to be retrofitted for accessibility, conflict sometimes arises between preservationists and disability advocates. An equally significant

² O'Hara, A., & Miller, E. (2000, August). *Going It Alone: The Struggle to Expand Housing Opportunities for People with Disabilities*. Boston, MA: Technical Assistance Collaborative, Inc. & Washington, DC: Consortium for Citizens with Disabilities Housing Task Force. Retrieved on September 20, 2004, from http://www.c-c-d.org/going_alone.pdf.

³ The Arc of Arkansas & United Cerebral Palsy (UCP) Public Policy Collaboration. (2004, July). *Housing for People with Disabilities: The Crisis Continues* (fact sheet). Washington, DC: The Arc & UCP Public Policy Collaboration. Retrieved on September 20, 2004, from <http://www.thearc.org/ppc/housingfacts.doc>.

⁴ O'Hara & Miller, 2000.

⁵ U.S. Department of Transportation, Bureau of Transportation Statistics. (2003). *Freedom to Travel* BTS 03-08. Washington, DC: Bureau of Transportation Statistics. Retrieved on September 13, 2004, from http://www.bts.gov/publications/freedom_to_travel.

obstacle is lack of awareness among the public about the difficulties people with disabilities face as they try to negotiate the physical environment.

Fortunately, there are many resources available at all levels of government to help communities address these and other obstacles to accessibility. Priority action steps in this area include the following: (1) increasing awareness among community members by providing them with sensitivity training so that they can experience first-hand the access problems people with disabilities face; (2) educating city planners and public officials about how lack of access affects elders and people with disabilities and what they can do as professionals to improve the situation; (3) advocating for variances to zoning ordinances to accelerate improved access to the built environment.

Provide work, volunteer, and education opportunities

A fundamental principle of Title I of the ADA is that people with disabilities who want to work and are qualified to work must have an equal opportunity to work. However, unemployment among people with disabilities remains unacceptably high. The 2004 National Organization on Disability (N.O.D./Harris Survey of Americans with Disabilities⁶ shows that working-age adults with disabilities are half as likely as working-age adults without disabilities to be employed (35% versus 78%), and people with severe disabilities are less likely to be employed than those with slight disabilities (21% versus 54%).

Priority action steps to increase employment opportunities for and encourage the hiring of people with disabilities include the following: (1) using technology to facilitate education and training programs, to provide telework opportunities, and to match qualified job candidates with employers; (2) increasing awareness among community members about the value of employing people with disabilities; (3) setting an example by hiring people with disabili-

⁶ National Organization on Disability (N.O.D.). (2004). "Key Indicators from the 2004 N.O.D./Harris Survey of Americans with Disabilities." Washington, DC: N.O.D. Retrieved on August 25, 2004, from http://www.nod.org/pdf/files/harris2004/harris2004_summ.pdf. More information on this survey is available at: <http://www.nod.org/content.cfm?id=1537>.

ties for positions within government agencies; (4) helping businesses make reasonable accommodations for employees with disabilities by providing them with needed funding and/or technical assistance; and (5) removing any remaining disincentives to work, such as the potential loss of health care, SSI, or other entitlements.

Ensure access to key health and support services

Results of a survey by the Henry J. Kaiser Family Foundation reveal that, despite their well above average use of health care services, individuals with disabilities face greater barriers to health care access than does the rest of the population.⁷ People with disabilities have trouble finding doctors who understand their disabilities and are less likely than the general population to receive the range of recommended preventive health care services. In sum, people with disabilities face a fragmented health care delivery system that does not respond to their wishes or needs.

Priority action steps in the area of health care include the following: (1) designing health care systems that are consumer directed and provide care coordination to ensure that the right kind of care is provided to beneficiaries; (2) allowing "money to follow the person" to the most appropriate and preferred care setting to create a more equitable balance between institutional and community-based services, eliminate barriers to care, and provide consumers with choice over the location and type of services provided; (3) integrating the delivery of acute and long-term care services to provide "seamless" high-quality, consumer-centered, and continuous care across settings and providers; and (4) providing support services that are linked to housing to increase the availability and efficiency of service provision.

Encourage participation in civic, cultural, social, and recreational activities

According to the 2000 N.O.D./Harris Survey of Community Participation, overall, "people with disabilities feel more isolated from their communities, participate in

⁷ Hanson, K., Neuman, T., & Voris, M. (2003, December). "Understanding the Health-Care Needs and Experiences of People with Disabilities: Findings from a 2003 Survey." Menlo Park, CA: The Henry J. Kaiser Family Foundation. Retrieved from <http://www.openminds.com/indres/kaisersurvey.pdf>.

somewhat fewer community activities, and are less satisfied with their community participation than their counterparts without disabilities.⁷⁸ The survey attributes the lower rates of participation among people with disabilities, in part, to lack of encouragement from community organizations. A community can hardly be called livable for people with disabilities if the people are not involved in the community's civic, cultural, or social activities.

The survey results suggest that it is not enough for community organizations to simply offer activities and provide information about them to people with disabilities. Thus the priority steps in this area include the following: (1) encouraging community organizations to actively reach out to people with disabilities to include them in activities, and (2) ensuring that people with disabilities have access to all of the opportunities that are offered to other members of the community.

It is reasonable to assume that communities will always face financial and structural obstacles to becoming more livable for people with disabilities. Intangible obstacles, like the public's lack of awareness and understanding of the difficulties people with disabilities face in their communities on a daily basis, are perhaps even more pervasive and difficult to overcome. But, as the successful community examples in the *Livable Communities for Adults with Disabilities* report illustrate, where there is political will, there are many possible, creative ways to surmount obstacles that prevent communities from being more livable for us all.

⁷⁸ Harris Interactive, Inc. (2000). 2000 N.O.D./Harris Survey of Community Participation. New York: Harris Interactive, Inc.

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