

# Livable Communities for Adults with Disabilities



National Council on Disability  
December 2, 2004

National Council on Disability  
1331 F Street, NW, Suite 850  
Washington, D.C. 20004

**Livable Communities for Adults with Disabilities**

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## NATIONAL COUNCIL ON DISABILITY

*An independent federal agency working with the President and Congress to increase the inclusion, independence, and empowerment of all Americans with disabilities.*

December 2, 2004

The President  
The White House  
Washington, DC 20500

Dear Mr. President:

On behalf of the National Council on Disability (NCD), I am very pleased to submit a report entitled *Livable Communities for Adults with Disabilities*. The report was developed with the advice of a consumer advisory committee from around the country.

The advances in America's policy and programs on behalf of citizens with disabilities have been inspiring. Notwithstanding the individual social policy and legislative achievements of the past 50 years on behalf of Americans with disabilities, however, we need to establish a cohesive public policy agenda in the coming years. We need a common vision, with clear objectives, that speaks to the strength of our commitment to our citizens and the quality of their lives, and one that addresses the challenges facing us in the years ahead.

Communities in the United States are faced with increasingly difficult choices and decisions about how to grow, plan for change, 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. One in five people in the United States will be over the age of 65 by 2030. 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 possible that the number of people aged 65 and older with disabilities will also grow, particularly those 75 years of age and older.

*Livable Communities for Adults with Disabilities* offers a compelling vision for our nation. It articulates the elements of a livable community, highlights existing examples of livable communities in the United States today, which can serve as models for others, and describes how communities can develop and sustain their livability features.

Our recommendations are in line with the focus of your New Freedom Initiative's emphasis on community integration, participation, and enhancement of the independence of people with disabilities at home, at work, and throughout the course of their daily lives. NCD stands ready to work with you and stakeholders inside and outside the government to see that the agenda set out in the attached report is implemented.

Sincerely,

Lex Frieden  
Chairperson  
National Council on Disability

(The same letter of transmittal was sent to the President Pro Tempore of the U.S. Senate and the Speaker of the U.S. House of Representatives.)

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## Executive Summary

*For the promise of full integration into the community to become a reality, people with disabilities need safe and affordable housing, access to transportation, access to the political process, and the right to enjoy whatever services, programs, and activities are offered to all members of the community at both public and private facilities.<sup>1</sup>*

### 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. People want to live in supportive communities that encourage independence and a high quality of life. To facilitate independence, people often need the same kinds of services. In addition, people 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 purposes of this 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 is inspired, in part, by a similar framework developed for the AdvantAge Initiative, a project that helps communities measure and improve their “elder-friendliness.”<sup>2</sup> 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 support 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.

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 this 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 affect 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 strategy 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 this 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.”<sup>3</sup> According to the Public Policy Collaboration, however, people with disabilities “face a crisis in the availability of decent, safe, affordable, and

accessible housing,”<sup>4</sup> 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.<sup>5</sup>

Model community efforts profiled in this report, which 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 transportation 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.<sup>6</sup>

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 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 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 Disabilities<sup>7</sup> 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 disabilities 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.<sup>8</sup> 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 somewhat fewer community activities, and are less satisfied with their community participation than their counterparts without disabilities.”<sup>9</sup> 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 community examples in this 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.



# **Chapter 1: Elements of Livable Communities for Adults with Disabilities**

## **An Introduction to Mr. Clyde Boger**

As public housing projects go, Amsterdam Houses in New York City is better than many. The location—a busy neighborhood close to one of the city’s cultural hubs—couldn’t be better. The housing complex’s 14 buildings are spaced widely apart, and the grounds are park-like. But despite their proximity to elegant theaters and concert halls, Amsterdam Houses can seem worlds away. Most residents have little in common with the well-dressed patrons who can afford to attend the cultural offerings and elaborate opening parties at neighboring Lincoln Center.

We arrived at Mr. Clyde Boger’s building at 2:00 p.m. on a cold weekday afternoon. The building’s intercom wasn’t working and the front door of the building was unlocked, but we could open it only after pressing against it with all our might. The elevator—which was graffiti-free—took us to the 11th floor. We knocked on the door of the apartment where Mr. Boger has lived for 53 years. Such long-term tenancy is not unusual at Amsterdam Houses: 92 percent of the 600 or so residents aged 65 and older have lived there for 30 years or more, and more than half of these for at least 50 years. Like Mr. Boger, the majority of older residents of Amsterdam Houses are people of color (88%), live alone (56%), and have incomes below 200 percent of poverty (63%).

Mr. Boger promptly opened the door and invited us in. He looked younger than his 85 years, and his darkened glasses and need to hold on to the wall and furniture to navigate through the apartment were the only visible indicators of his many health problems. Mr. Boger is legally blind and has glaucoma. He had had successful cataract surgery in both eyes more than three decades ago, but after having a stroke in 1983, he lost most of his vision. He also has hypertension, high cholesterol, diabetes, and a heart pacemaker. But he cheerfully led us into the cramped living room of his tiny apartment, and as we sat on the small sofa, we observed a cloud of dust rise in the streaks of sunlight streaming into the overheated room.

As we waited for Mr. Boger to get comfortable, we looked around and imagined that the room had changed little since 1951, when he and his wife moved in. Now Mr. Boger lives alone. His

wife, a teacher, died in 1985 of breast cancer, and Mr. Boger retired early to care for her, forfeiting some retirement income as a result. Then, their only son, who worked for the city's transit department, died seven years later of colon cancer at the age of 41. We wanted to know how he managed on his own, given his multiple health problems. In response, Mr. Boger told us about his routine:

I get up at about 9:30 and make myself breakfast—usually cereal or toast. Then I sit in the living room and listen to the news on the radio or television or to my jazz records—I used to hang out at the Cotton Club and the Savoy when I was young, you know. The Meals on Wheels people deliver lunch between 12:30 and 1:00—they were here just before you came. After lunch, I take a nap, and in the afternoon I have to take my medication, for my high blood pressure, cholesterol, diabetes, and bladder problems. They also gave me three different eye drops. Then I make dinner—last night I made chicken fricassee—and I listen to the radio or TV, mostly news, until bedtime.

Noticing a crutch in the corner of the room, which he did not use while we were in the apartment, we ask Mr. Boger how often he goes out:

Oh, I go to the Veterans Administration Medical Center four to five times a month. I usually go by taxi. Sometimes a volunteer from the community center comes around and walks me to the center for meals or activities, but sometimes I just take a taxi over there—it's just three dollars. A volunteer from the democratic club comes by to take me to meetings and brings me back. Did you know I was a coordinator for the Board of Elections for 40 years, and I started the first tenant patrols around here in the 1970s?

We ask Mr. Boger about food shopping and other household chores:

I've got plenty of neighbors and friends who always stop by and ask if I need something from the store. And when my wife was alive she made friends with this family that had a little daughter she loved like she was her own—you know, the daughter we never had. Now that little girl is 43 and has two sons of her own, 4 and 13. She lives down the block and she calls me every day and comes in and does the cleaning and shopping for me. Her

mother, who's now in her 60s, does my laundry. I sure enjoy it when those boys come over!

When we ask him whether he plans to get surgery for the glaucoma, he shakes his head “no” and explains:

I'm 85 years old. I can see what I need to see. I get along fine and I don't have any problems. I have food to eat, clean clothes, a decent place to live, friends nearby, and whenever I need something I know who to call.

Certainly, these are the basic ingredients of an independent life. But then he tells us the harrowing story of what happened to him just a few months ago when he passed out at home because his blood sugar was so low. He couldn't see but managed to crawl to the telephone and call his neighbor. Luckily she was home and was able to call 911 and summon an ambulance for him.

We chat a bit longer, mainly about Mr. Boger's favorite topic—politics. He is well informed and freely voices his opinions on the top issues of the day. Before we know it, it is 4:00 p.m., and we realize that we have made Mr. Boger miss his nap. We thank him for his time and get up to leave. Although he has many friends and claims not to be lonely, we can tell that he enjoyed having visitors and the opportunity to talk. We stop at the door, shake his hand good-bye, and on the way out wonder how long Mr. Boger's proud independence will last.

## **A Population Growing Older**

Mr. Boger began his long education in self-reliance at an early age. He was orphaned as a child and his four sisters abandoned him by the time he was 7 years old, leaving him to live with neighbors and fend for himself. He worked his way through school, including three years of college, and became economically independent. Happy and productive in his youth and middle age, Mr. Boger's life took a tragic turn when his wife was diagnosed with breast cancer. During the years after she died, he faced further losses—of his son, his robust health, and his sight and mobility. Mr. Boger's story is not unusual. Like Mr. Boger, 42 percent, or more than 1.4 million

Americans 65 years of age or older, live alone; 14 percent, or more than 4.7 million, have a sensory disability involving sight or hearing; and 20 percent, or more than 6.7 million, have difficulty going outside the home.<sup>10</sup>

Several studies published in recent years<sup>11</sup> show that overall disability rates for people 65 and older are falling, although some researchers believe that these falling rates mostly apply to Instrumental Activities of Daily Living.<sup>12</sup> In either case, the fact remains that people are living longer lives today than ever before and one in five people in the United States will be over the age of 65 by 2030. This combination of trends raises the prospect that the number of people 65 and over with disabilities will grow along with the general population of elders, particularly among those 75 years of age and older. Aside from genetic make-up, several risk factors—all of them present in Mr. Boger—increase the chances that a person will become disabled as he or she grows older:

- **Age:** While only 18.6 percent of people 16 to 64 years of age have a disability, 41.9 percent of those aged 65 and older have a disability. Among those aged 75 and older, the percentage is even higher—54 percent.<sup>13</sup>
- **Race:** Among those 65 and older, Asians and non-Hispanic whites have the lowest disability rates (40.8% and 40.6%, respectively), while blacks and Native Americans have the highest (52.8% and 57.6%, respectively).<sup>14</sup>
- **Income:** Older people with low incomes are at higher risk for disability. While 40 percent of those with incomes above the poverty level have a disability, 56 percent of those with incomes below the poverty level have a disability.<sup>15</sup>

To accommodate these demographic trends, changes must be made that, according to the American Association of Retired People (AARP) *Report to the Nation on Independent Living and Disability*, cause a “major improvement in the quality of life” for people with disabilities.<sup>16</sup>

### **Loss of Independence: A Common Concern**

Mr. Boger worked hard all his life. He was a combat medic in France during World War II and upon returning home worked as a medical technician for the remainder of his career. He was an

exceptionally active member of his community and provided countless volunteer hours to various causes. He was a full-time caregiver to his wife and his son. And, until his stroke, which left him virtually blind at age 64, he was not disabled in any other way. To the casual observer, Mr. Boger, who lost his vision in his seventh decade after a lifetime of sight, might seem to have little in common with a younger person who has been living with blindness since birth. People with disabilities are just as diverse as people without disabilities, if not more so. According to *Beyond 50 2003 A Report to the Nation on Independent Living and Disability*, which was based in part on the 2000 AARP/Harris Interactive Survey of Persons 50 and Older with Disabilities<sup>17</sup> survey of more than 1,100 people aged 50 and older with disabilities, people with disabilities may be “an even more heterogeneous population because of wide variations in the types of disabilities they experience, the age of onset of these disabilities, and their life experiences.”<sup>18</sup> But, as the report continues, when people with disabilities talk about what they most value—and fear—in life, cross-cutting themes become evident:

Loss of independence, their number one fear, and issues of control over decision making emerge as major themes. Another theme is the desire to engage in ordinary activities that help connect us to others and to take care of ourselves as we age, such as keeping in touch with family and friends, doing household chores, and engaging in exercise and physical activity.<sup>19</sup>

And, when it comes to rating their communities on livability for people with disabilities, the following emerged:

Overall, respondents rate their communities as meriting only a B/C+ as a place to live for people with disabilities or health conditions such as theirs. Persons age 50 to 64 and those with very severe disabilities are the groups most likely to give their communities a “D” or “below average.”<sup>20</sup> ...Lack of dependable and accessible transportation is the biggest problem. The next most important problem is the lack of community services to “help you maintain your independence as you grow older.”<sup>21</sup>

## **Making Lifelong Independence Possible**

*For the promise of full integration into the community to become a reality, people with disabilities need safe and affordable housing, access to transportation, access to the political process, and the right to enjoy whatever services, programs, and activities are offered to all members of the community at both public and private facilities.<sup>22</sup>*

According to the AdvantAge Initiative National Survey of Adults Aged 65 and Older, 93 percent of older people say that they would like to live in their own homes as independently as possible for as long as possible.<sup>23</sup> The same holds true for adults with disabilities. According to the AARP/Harris survey, “persons 50 and older with disabilities, particularly those age 50 to 64, strongly prefer independent living in their own homes to other alternatives.”<sup>24</sup> Even if they were to move, 69 percent of people aged 50 and over say they would prefer to move to another home or apartment.<sup>25</sup> As the AARP/Harris survey illustrates, people with disabilities want access to the same places, things, and opportunities that people without disabilities are able to access. They want to feel safe and to learn, work, and contribute in significant ways. They want to participate in social activities and have relationships with others. In short, people with disabilities want to achieve their full potential and live meaningful lives in communities that actively include, rather than passively isolate, them. The extent to which people with disabilities are able to achieve these goals depends on a number of factors, some of which can be discerned in Mr. Boger’s own story.

The following factors allow Mr. Boger to continue living as independently as possible in the community.

**Affordable and accessible housing:** While most people might not choose to live in public housing if they had other options, for Mr. Boger and other elders living in the Amsterdam Houses complex, this is a blessing. Mr. Boger spends \$495 per month on rent for his apartment, a bargain by New York City standards, but nonetheless one that takes a big bite out of Mr. Boger’s civil service annuity of \$1,471 per month. Still, this is acceptable to him, given his modest needs in other areas of his life. As he comments on his income, “It’s really not enough, but I can survive on it.” For the time being at least, accessibility is not an issue for Mr. Boger:

There are no stairs leading into his building, and the elevator takes him within three or four steps of his front door. If his disability status were to change, however, access might well become a problem.

**Comprehensive health care:** Perhaps the most important factor that makes Mr. Boger's income sufficient is that he does not spend any of it on health care. With his multiple health problems that must be monitored continually, Mr. Boger is fortunate to be eligible for care at the Veterans Administration Medical Center.<sup>26</sup> The Medical Center has a Visual Impairment Service Team Program (VIST) that helps legally blind veterans adjust to severe vision problems and a Home-Based Primary Care Program in which a team of health care professionals provide at-home care to patients. Mr. Boger, however, prefers to get his care on site. He goes to the Medical Center several times a month to see the cardiologist for his pacemaker, the podiatrist for diabetes-related foot care, the urologist for bladder problems, and other doctors and counselors as needed, all at the same location. Every three months he picks up his medications at the Medical Center. All this care is provided to Mr. Boger without any out-of-pocket expenses.

**Accessible transportation:** Trips to the Medical Center are Mr. Boger's principal outings. He tried Access-A-Ride (a paratransit service in the city) a couple of times, but the driver was late, he says, and not very courteous, so Mr. Boger prefers to take a taxi—truly an on-demand transportation system. Other than his crutch, which he uses when he leaves the apartment, he does not need assistance to take the elevator down to the street. Usually he is able to hail a taxi right outside his building. Sometimes, if a taxi doesn't come by when he needs it, he walks a half-block down to the corner to find one. He complains about this, but, in a pinch, the short walk is still manageable for him. He returns home by taxi as well. Although a taxi ride from West 65<sup>th</sup> Street, where Mr. Boger lives, to East 23<sup>rd</sup> Street, where the Medical Center is located, is expensive for someone of modest means like Mr. Boger, the fact that he takes a cab only about once a week makes it affordable to him. A less-expensive alternative would be the city bus system, which is heavily used by older people. All of the vehicles in the fleet are "kneeling" buses, which are also wheelchair accessible, and they run 24 hours a day, seven days a week. Although it is often slow-going in traffic, the bus is a safe, affordable, and pleasant method of

transportation for countless older people in the city. The fact that transportation options exist in his community is a key factor in Mr. Boger's ability to stay independent.

**Community-based services:** Although Mr. Boger did not talk about it much during our interview, we know that professionals in the community are looking out for him and are available whenever he needs them. The Lincoln Square Neighborhood Center (LSNC), a few short blocks from Mr. Boger's front door, provides recreation, education, and health-related services to residents of all ages living in the Amsterdam Houses and surrounding community. LSNC has a Naturally Occurring Retirement Community-Supportive Services Program (NORC-SSP), financed through public-private partnerships that combine revenues and in-kind supports to organize and provide a range of coordinated health care and social services and group activities on site. A social worker at LSNC is very familiar with Mr. Boger's situation and monitors it without being intrusive. She arranged for Mr. Boger to receive Meals on Wheels lunches, and she sees to it that staff members or volunteers pick up Mr. Boger at his apartment and walk him to the center for meals and activities whenever he feels like joining the many other seniors who congregate at the nicely appointed center. The fact that it is located within the housing complex makes it accessible to all residents of Amsterdam Houses, regardless of age and ability.

**A social network:** Ironically, it is Mr. Boger's reliance on others that enables him to continue living independently in his own home. While still able to meet his personal care needs, like dressing, bathing, and getting around inside his home—and even outside occasionally for very short distances—Mr. Boger is unable to perform some of the instrumental activities of daily living, such as food shopping or doing housework, without the help of others. On several occasions in the past, Mr. Boger availed himself of home attendants from a local home care agency, but he says he prefers to be assisted by people he knows—his neighbors and friends. Fortunately for him, he has a wide social network that he and his family cultivated over a period of years, both casually in the housing development where they lived and through Mr. Boger's extracurricular activities, such as his involvement in union activities (he was president of the union for eight years) and through his volunteerism with political organizations in the community. The dense, mixed-age urban neighborhood in which Mr. Boger has resided for more



than 50 years, although a drawback in some other respects, has facilitated his interaction with people of all ages and mitigated the isolation that so many older people face. Thanks to this extensive support network, Mr. Boger is managing remarkably well at home.

**Contributions to the community:** Despite his health problems, Mr. Boger continues to contribute to his community—a habit he got into a long time ago. Claiming to be “the oldest person living here,” Mr. Boger acts as the unofficial grandfather to the children and teenagers in his building, as well as the two sons of the woman who helps him so much at home. He continues to attend meetings of the democratic club, voice his views, and act as a mentor to the younger attendees, who he thinks needs some lessons in principles and integrity. These activities are certainly less extensive than what he was used to in the past, but at this point in his life, they seem just about right.

As Mr. Boger’s situation demonstrates, people who become disabled in later life are able to continue living in and contributing to the community when the environment, health and social services systems, and so-called “informal care network” support their independence.

### **Adults with Disabilities Speak Out**

The elements that help keep Mr. Boger independent and the community “livable” for him are not very different from those that make communities livable for younger adults with disabilities. The AARP/Harris survey, for example, demonstrates that many of the factors that make life in the community possible for 85-year-old Mr. Boger are applicable to younger adults with disabilities. Keeping up social connections, living in affordable and accessible homes, being able to travel outside the home at will, having access to transportation when needed, participating in outside activities are some of the key factors that AARP/Harris survey respondents say help them maintain their quality of life in their communities.<sup>27</sup>

We met with a group of 12 racially diverse people with disabilities, ranging in age from 30 to the late 50s (with one individual in his 70s), in Silver Spring, Maryland, to solicit opinions about the various aspects of communities that make them good places for adults with disabilities to live, as well as those that impede livability. In the course of the two-hour discussion, these 12 focus

group participants echoed the responses provided by respondents to the AARP/Harris survey, and they made it clear that aspects of communities that facilitate independent living are those they cherish the most.

**Affordable, accessible, and safe housing:** Throughout the focus group session, the theme of accessible, affordable, and safe housing appeared and reappeared. Participants repeatedly stressed the importance of living in a place of their own, and those who lived alone emphasized how much they “like it.” Two of the participants felt they were “blessed” to have moved into their current residences from nursing homes, thus regaining the independence that had been lost when they lived in an institution. One participant felt especially grateful to have a place of her own after a six-month period of homelessness, including one month she spent in a shelter. Focus group participants said that satisfaction with housing arrangements is the primary motivator to stay in or move from their communities. While most of the participants were living in subsidized housing that was affordable to them, some had to initiate modifications to make their homes fully accessible. Participants identified neighborhood crime and the ability to exit from one’s home easily in case of fire or other emergency as safety issues.

**Ready access to transportation and the physical environment:** Dependable public and special transportation was mentioned frequently by the focus group participants as being essential for travel around the community—to work, to the store, to the doctor, to church, and elsewhere. Proximity of stores, libraries, laundry facilities, recreation, and other necessities helps make life easier as well, the focus group participants said. Some described special transportation as consistently unreliable, with the burden frequently placed on the individual to make travel accommodations because of the lack of a central information system. Sidewalks and curb cuts and thorough snow and ice removal were mentioned as mobility facilitators. Some participants expressed frustration over the lack of planning and provisions for accessibility during the ongoing process of redevelopment in a number of communities. While some accommodations for pedestrians are made during construction, they are usually unsuitable for people in wheelchairs.

**Work, education, and volunteer opportunities:** Participants in the focus group described their eagerness to learn new skills and work, the challenges and rejections they faced when looking for

work, and the fears that prevent them from seeking work, including the fear of losing Medicaid, Medicare, or Supplemental Security Income (SSI) benefits. Participants were eager to embark on new careers and hoped to be provided with learning opportunities appropriate for their needs. Several participants expressed how important it was for them to contribute to the community in whatever way they are able.

**Social and civic engagement:** A “community” is frequently defined in terms of its physical location, but as the focus group participants pointed out, the definition should include the social “climate” as well. Several members of the group stressed that having neighbors who are friendly, or at least respectful, enhances the environment, making it a more welcoming and pleasant place to live. For some, living in a racially and ethnically diverse community is a strong preference, and others voiced the importance of going out and actively socializing with neighbors during block parties or other neighborhood events. Several of the focus group participants pointed out that measures taken to improve life for adults with disabilities confer benefits on others in the community as well, and any advocacy on the part of people with disabilities should be inclusive. As one participant put it: “We have a voice in the community, and we need to use it to help other people, not just ourselves.”

### **The Livable Community for Adults with Disabilities Framework**

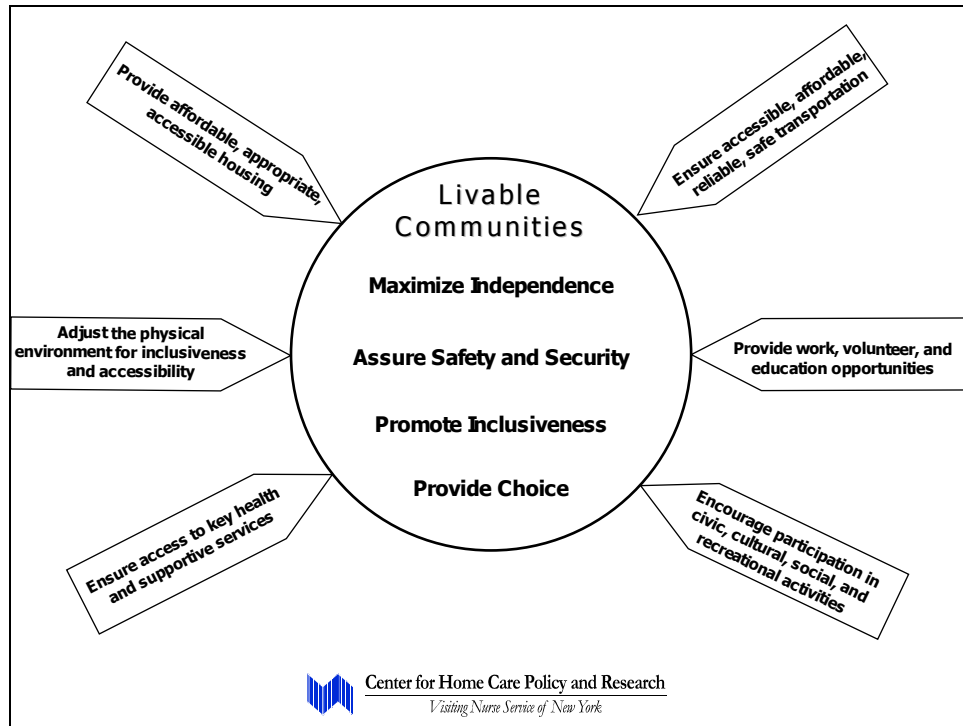
Community is a general term that people tend to define for themselves, depending on circumstances. Speakers of a particular foreign language in a U.S. city, for example, might consider themselves and their linguistic compatriots a “community,” regardless of where in the city they live. More frequently, however, community is defined geographically and refers to the immediate area in which people live, such as a neighborhood. The neighborhood may refer to a larger part of the city or town, such as the “near north side” of Chicago or Georgetown in Washington, D.C.; a smaller section of the city, such as a series of contiguous blocks; or even, as in Mr. Boger’s situation, a set of buildings located in a particular neighborhood.

Livable community also has multiple definitions that change depending on the context and such considerations as community capacity, organizational goals, and the needs and desires of a particular group of citizens.. For example, the American Institute of Architects’ (AIA) definition

of a livable community is oriented toward urban planning and community development.

According to the AIA, for a community to be considered livable, it must “create a neighborhood identity, provide choices, conserve the open landscape, plan on a human scale, encourage mixed-use development, vary transportation options, preserve urban centers, and protect environmental resources.”<sup>28</sup> With a specific constituency in mind—older people—the AdvantAge Initiative uses a framework with four “domains” to define a livable, “elder-friendly” community. Thus, in this context, a livable community for older people is one that (1) addresses basic needs for such things as food, transportation, and information; (2) optimizes physical and mental health and well-being by reducing barriers to care and promoting wellness; (3) maximizes independence by providing resources to help the elderly live comfortably at home; and (4) promotes social and civic engagement so that they remain connected to others and participate in community life.<sup>29</sup> In the AdvantAge Initiative, these four “domains” refer to community capacity relating specifically to older community residents. It is not difficult, however, to see that a community that successfully addresses these four domains becomes a good place for adults of all ages and abilities to live.

For purposes of this study, we have created a framework that defines the elements of a “livable community” for another specific constituency—adults with disabilities (see Figure 1). This framework synthesizes the observations made about Mr. Boger’s situation, comments made by focus group participants, results of the AARP/Harris survey, and the 2000 National Organization on Disability (N.O.D.)/Harris Survey of Americans with Disabilities, as well as additional background research conducted for this study. In the next chapter, we will highlight examples of communities that have been addressing one or more of the elements of this framework and explore what these communities did to become more livable for residents with disabilities.



**Figure 1.** Framework of a livable community for adults with disabilities.



## **Chapter 2: Provide Affordable, Appropriate, Accessible Housing**

Nine years ago, when Dennis Fitzgibbons, Director of Operations at Alpha One, a Center for Independent Living with offices in Bangor and South Portland, Maine,<sup>30</sup> and his family moved from Massachusetts to Yarmouth, Maine, they contacted a real estate agent to help them find a ranch house with wide doorways and large bathrooms to accommodate Dennis' wheelchair. Thus began an odyssey that eventually took the family through half a dozen real estate agents, who just could not understand the family's needs, and visits to countless houses that did not come close to being accessible. "We would show up to see a house that the agent said was perfect for us, only to find that it was a two-story Cape," Dennis explains. "Oh, I thought you would really like this house," the agent would say, by way of explanation. After many such false leads, the Fitzgibbons family met an agent "who really stuck with us," says Dennis. "She was bound and determined to find us a house and really hung in there. But I remember that at one point, totally frustrated, she threw up her hands and said 'Where on earth do people with disabilities live anyway?'"

In time, the family did find a home that met most of their requirements, but some exterior modifications needed to be made, including installation of a ramp leading to an entrance door at the back of the house and repaving the driveway area to create a smooth surface for Dennis' wheelchair. An indoor ramp had to be constructed in place of the original stairways that connected two parts of the house, but luckily no other major interior renovations, like widening doorways or renovating bathrooms, were required. Still, the Fitzgibbons family spent about \$20,000 to make the necessary modifications. "Because we moved from Massachusetts, where home costs are higher, we had the money for a down payment on a new home and a little left for the renovations," Dennis explains. "There are some home modification programs available for those with lower incomes, but we were not eligible." If they had needed to take out a loan to pay for the renovations, however, they would have been eligible for the state's Kim Wallace Adaptive Equipment Loan Program. This program is a \$6.5 million revolving loan fund in which eligible residents of Maine may borrow up to \$100,000 to purchase assistive technology (AT) or adaptive equipment to enhance their independence.<sup>31</sup> Home renovations are an acceptable adaptation.

The Fitzgibbons' home is now thoroughly livable, although Dennis says that some day he would like to redo the kitchen. But that project will have to wait. "With two children at home," says Dennis, "we have other priorities at the moment!"

## **A Home of One's Own**

*Independence and integration are among the most important values and goals shared by people with disabilities, their families, and advocates. A home of one's own—either rented or owned—is the cornerstone of independence for people with disabilities. When a person with a disability has a decent, safe, and affordable home, then he or she has the opportunity to become part of the community. With stable housing, people with disabilities are able to achieve other important life goals, including education, job training, and employment.<sup>32</sup>*

This theme was clearly echoed by participants in our focus group, who repeatedly stressed the importance of living in a place of their own and described the physical environment that allows them to do so, as well as the challenges they face. Satisfaction with housing arrangements, focus group participants said, was the determining factor for remaining in or moving from communities, and this satisfaction depended on two key factors: housing affordability and accessibility. Most of the focus group participants live in subsidized housing, which some had to modify themselves to be able to live there. Across the nation, however, people with disabilities "face a crisis in the availability of decent, safe, affordable, and accessible housing,"<sup>33</sup> because there simply aren't enough units to meet demand, particularly for people with low incomes who require subsidies to help pay for housing.

Over the past seven years, the number of renter households with severe housing problems<sup>34</sup> declined for every group eligible for federal housing assistance except for low-income people with disabilities. The Consortium for Citizens with Disabilities Housing Task Force and the Technical Assistance Collaborative estimate that as many as 1.8 million people with disabilities who receive SSI benefits may have severe housing problems.<sup>35</sup> They are not receiving federal housing assistance and cannot get on subsidized housing waiting lists. "Instead they are living in congregate settings or in seriously substandard housing; still living at home with aging parents



who do not know what will happen to their adult child when they can not longer provide for them; or are either homeless or at risk of becoming homeless.”<sup>36</sup>

Many low-income people with disabilities who have unmet housing needs are aged 65 and older. According to a recent report produced by the Commission on Affordable Housing and Health Facility Needs for Seniors in the 21<sup>st</sup> Century, there are nearly six times as many seniors with unmet housing needs as currently are served by rent-assisted housing, and waiting lists for many types of subsidized housing are long. Citing *Housing Our Elders*, a report produced by the Department of Housing and Urban Development (HUD) in 1999 based on the 1995 American Housing Survey, the Commission reports that “approximately nine elderly applicants were on waiting lists for each Section 202 unit that became vacant within a year.” In addition, they report that hundreds of thousands of Section 8 assisted units in senior housing are in danger of disappearing because they are considering “opting out” of the HUD program.<sup>37</sup>

The vast majority of senior homeowners have paid off their mortgages; however, because of rising property taxes and maintenance costs, there are many who are at risk of losing their homes. Other seniors are not able to continue living in their homes without making significant structural changes to accommodate one or more functional limitations, and some of these modifications may be quite costly to make. According to *Housing Our Elders*, when the American Housing Survey was conducted in 1995, “over 1 million elderly households...reported needing home modifications.”<sup>38</sup> Even if disability rates continue to decline, the number of older people with a disability will grow from 6.2 million in 2000 to 7.9 million in 2020,<sup>39</sup> largely because the population of older people will climb dramatically in the next decade. The need for housing modifications undoubtedly will grow commensurately with this population increase.

The lack of affordable, accessible housing is due to a number of factors, including the following:

- The high costs of land, materials, labor, and “retrofitting” existing housing with accessibility features
- Land use and building regulations in local communities that discourage multi-unit housing development

- Public resistance and sometimes outright opposition to building new housing or converting older buildings into housing suitable for a range of incomes and abilities
- Few incentives for private developers to build affordable and accessible housing
- Lack of demand from the general public for accessibility features such as wider doorways because they do not see the value of such features or assume they would raise the price of already expensive housing

There are a range of federal regulations that protect people with disabilities in the following ways:

- Prohibit housing discrimination on the basis of disability
- Set accessibility standards for new or rehabilitated multifamily housing
- Ensure that programs are accessible to people with disabilities
- Provide incentives to developers for the inclusion of accessibility features in the federally subsidized single-family homes they build

Some new pilot federal programs, such as Project Access,<sup>40</sup> are trying out other mechanisms to expand access to housing for people with disabilities.

Critics say, however, that inadequate funds and lack of a coherent and comprehensive federal housing policy are major obstacles to increasing the stock of affordable and accessible housing in the United States.<sup>41</sup>

To make matters worse, the nation’s existing “affordable housing programs are not organized or delivered systematically, but rather through myriad complicated programs and housing agencies that have no relationship to one another. Navigating through this maze has proved very difficult for the disability community.”

While there are some provisions in federal law and regulation designed to foster collaboration between government housing officials and the disability community—

including the Consolidated Plan—housing advocates for people with disabilities have not learned how to capitalize on them.<sup>42</sup>

Given the magnitude of the affordable/accessible housing “crisis,” effective solutions are going to require creative, out-of-the-box thinking and the involvement of multiple stakeholders, including state and local governments, private developers, consumer advocates, and consumers. A number of states, counties, and cities are making headway in expanding affordable and accessible housing for people with disabilities. While approaches for addressing these housing issues vary depending on local contexts, two common elements exist in most successful efforts:<sup>43</sup>

- The creative use of all available affordable housing programs to expand homeownership and rental housing options; and
- Strong partnerships and collaborations between the affordable housing system and the disability community to ensure that the housing created will meet the housing needs and preferences of people with disabilities.

Efforts to increase the availability of affordable and accessible housing generally fall into three categories:

- Programs that provide incentives to maintain existing affordable housing units and/or increase affordable housing stock in the community
- Programs that help people with disabilities and seniors remain in the homes where they currently live or rent or buy affordable and accessible housing
- Programs that provide incentives to incorporate accessibility features into existing or new housing stock

Following are several examples of states, counties, and cities that have implemented significant, replicable strategies to expand affordable and accessible housing for residents with disabilities. Partnerships figure prominently in some of them, including partnerships between the disability and aging communities. These two groups often find that they are, in fact, on the same side, representing the same constituency—people with disabilities that have housing needs.

**Programs that provide incentives to maintain existing affordable and accessible housing units and/or increase affordable/accessible housing stock in the community.**

**Austin, Texas. Austin's S.M.A.R.T.™ Housing Initiative provides financial incentives for private construction of affordable, accessible housing located close to public transportation.**<sup>44</sup> The City Council adopted the S.M.A.R.T. Housing Initiative in April 2000, with the goal of motivating production of S.M.A.R.T. Housing.<sup>45</sup> S.M.A.R.T. refers to Safe, Mixed-Income, Accessible, Reasonably Priced, and Transit-Oriented Housing. The initiative was an immediate success. In the first year, the City Council expected to have 600 new single-family or multifamily housing units under development review. By September 2001, more than 6,000 single-family or multifamily units were under the review or inspection process. By September 2004, 4,000 new single-family or multifamily units had been completed. In 2004 alone, approximately 1,600 to 1,700 units were completed, with 78 percent of them reasonably priced, nearly doubling the 40 percent target.<sup>46</sup>

- **Safe:** The development complies with the land development code and the adopted building codes.
- **Mixed-Income:** The development includes at least 10 percent reasonably priced housing units. All of the units meet S.M.A.R.T. Housing standards.
- **Accessible:** Developments meet federal, state, and Austin's visitability standards for accessibility.<sup>47</sup>
- **Reasonably Priced:** A percentage of the units must be rented or sold to families whose incomes do not exceed 80 percent of Austin's median family income, and who do not spend more than 30 percent of the family's income on housing. Reasonably priced rental units must be affordable for at least five years; homeownership units must be affordable for at least one year.
- **Transit-Oriented:** Requirements are set for proximity and frequency of public transportation; porch size and location; street orientation of the house; design of parking areas, driveways, and walkways; and pedestrian and vehicular connections.

Further recommendations are provided for transit amenities (e.g., bus shelters), sidewalks, landscaping, lighting, fencing, common spaces, parking, building facades, and mixed-use spaces (e.g., commercial uses).

The goals of S.M.A.R.T. Housing are to stimulate the development of affordable housing by providing incentives to private developers and encourage collaboration between the public and private sectors. To achieve these objectives, the S.M.A.R.T. Housing Policy Initiative accomplished the following:

- Designated the Austin Housing Finance Corporation (AHFC) as the lead agency responsible for fostering partnerships with the homebuilding industry to develop, finance, construct, renovate, and operate affordable housing in the City of Austin, thus creating clear accountability for results.
- Designated the Neighborhood Housing and Community Development Department (NHCD) as the lead agency on housing policy issues. It is a single point of contact for residents, builders, and city staff. NHCD is a city department that fosters partnerships with neighborhoods and ensures that S.M.A.R.T. Housing Developments “are sited in a manner consistent with applicable federal and city policies.”
- Gives the AHFC first dibs on surplus city property at below market prices, thus encouraging construction of more reasonably priced homes.
- Allows full or partial fee waivers for developments that make a portion of their units reasonably priced. These include Water and Wastewater Capital Recovery fees, Development Review and Inspection fees, and Public Works Construction fees.
- Encourages homeowners and contractors to maintain and remodel existing housing to meet safety and sanitation standards with housing rehabilitation guidelines.
- Provides rehabilitation code education.
- Addresses code violations and illegal practices.
- Encourages collaboration and coordination among city departments.

For more information, see the S.M.A.R.T. Housing<sup>TM</sup> Policy Resource Guide, prepared by the Neighborhood Housing and Community Development, at <http://www.ci.austin.tx.us/ahfc/downloads/smartguide.pdf>.

**Little Rock, Arkansas. The Arc of Arkansas provides affordable, accessible housing to people with and without disabilities in renovated historic buildings.** The Arc of Arkansas is “a statewide organization providing support, housing, advocacy, education and leadership to people with developmental disabilities and their families.”<sup>48</sup> Their goal is to integrate people with disabilities into the community. The Arc used Historic Preservation Tax Credits together with federal, state, and local funds<sup>49</sup> to finance the renovation of abandoned buildings on the National Register of Historic Places. To date, The Arc has renovated three properties in Little Rock with a total of 106 rental units in proximity to public transportation. Trinity Court Place serves low-income renters while Eastside Lofts and Westside Lofts serve renters with mixed-income levels. All of the apartments contain universal design features and are marketed to the general population. Overall, about 40 percent of renters are people with disabilities. A brief description of the properties follows.

- **Trinity Court Place Apartments**<sup>50</sup>—The building was built in 1911 and first housed a health maintenance organization (HMO), then a nursing home. Trinity Court Hospital donated the building to The Arc, which in turn partnered with First Security Vanadis Capital, LLC to conduct the \$2.1 million renovation. Renovation of the building, which would become Trinity Court Place Apartments, began in November 1998. In September 1999, the first tenants moved into the 22-unit independent living facility for low- to moderate-income people with developmental disabilities and their families. The complex includes accessible one- and two-bedroom apartments and includes unique features such as “lower peepholes, lower wall cabinets, wider hallways and walkways, detachable undersink cabinets, toilet seat and bathtub grab bars, and a high-tech, keyless entry system.”<sup>51</sup> The complex also includes common spaces, such as a community room with full kitchen amenities, art gallery area, classroom, veranda, and courtyard.

- **Eastside Lofts**<sup>52</sup>—Little Rock High School (known as East Side High School) was built in 1904. The Arc of Arkansas partnered with Bell/Corley Investments to purchase the school, and contracted with First Security Vanadis Capital, LLC to conduct the \$3.6 million renovation of the school into 41 affordable loft apartments for people with and without disabilities. The apartments, which are fully compliant with Americans with Disabilities Act (ADA) requirements, opened in January 2002. In January 2004, rents for the one-, two-, and three-bedroom units were listed at \$220–\$925 for people who met the income requirements.<sup>53</sup> After Bell/Corley recouped on their investment, the ownership of the property went to The Arc.
- **Westside Lofts**<sup>54</sup>—Westside Junior High School, built in 1917, was renovated in 2003 and transformed into 43 apartments with universal design features. The development team of Dover Dixon Horne, Fennel Purifoy Hammock, and Champion Builders and Herron Horton Architects put together this \$5 million project, with consulting services provided by the First Security Vanadis Capital, LLC.

A fourth project is under way.<sup>55</sup> The Arc purchased St. Anthony's Hospital in Morrilton from the Historic Register. The building is at the base of the Ouachita mountains and overlooks the river valley. Renovation is planned for May 2004 for 30 mixed-income, accessible apartments for a community of people age 55 and older. The purchase price was built into the project cost, and The Arc will get the money for acquisition back when construction begins. After 15 years, when the requirements of the Low-Income Housing Tax Credits end, The Arc will refinance the remaining bank debt and become the sole owner. Income received from the properties will be used to manage the properties and to help The Arc maintain financial stability.

Additional efforts are under way to promote universal design in Arkansas. With \$100,000 in seed money from the legislature, The Arc has an agreement with the University of Arkansas School of Architecture to create a universal design center that will train architects, engineers, developers, and investors. The Arkansas Development Finance Authority provides incentives to developers and contractors to use universal design, and

First Security Vanadis Capital, LLC continues to encourage clients to use universal design.

For more information, see The Arc of Arkansas Web site at <http://www.arcark.org>.

**Programs that help people with disabilities and seniors remain in the homes where they currently live or rent or buy affordable and accessible housing.**

**Alexandria, Virginia. Alexandria and other Virginia communities use the Virginia Real Estate Tax Relief Program for Elderly and Disabled Persons to help reduce housing costs for thousands of Virginia residents.**<sup>56</sup> The Virginia Real Estate Tax Relief Program for Elderly and Disabled Persons has been in effect since the early 1990s.<sup>57</sup> It is a state law that is administered by local jurisdictions. The real estate tax relief program was implemented to prevent people living on fixed incomes from moving out of their homes because of rising property taxes.

To qualify for real estate tax relief or deferral, residents must meet certain eligibility requirements. Applicants must be 65 years or older, or permanently and totally disabled. They must fully or partially own the property and occupy it as their sole residence. Applicants in a hospital, nursing facility, or other institution still qualify as long as they don't rent out their property. Residents also must meet specific income requirements. In 2004, the state income limit was \$62,000 and the state asset limit was \$240,000.

In Alexandria, residents qualified for a full or partial tax exemption in 2004, depending on their combined gross household incomes<sup>58</sup> in 2003. People qualified for a full tax exemption if their income did not exceed \$40,000, a partial tax exemption of 50 percent of taxes owed if their incomes did not exceed \$50,000, or a partial tax exemption of 25 percent if their incomes did not exceed \$62,000. Applicants approved for a partial exemption may defer the remaining balance of taxes owed. Interest accrues on the unpaid taxes at 5 percent per year from the date of the deferral until the taxes are fully paid, usually when the property is sold or when the owner is deceased.



Applicants must reapply every three years by completing a multipage application with detailed income information. During the intervening two years, applicants complete a simpler form that asks about any changes since the previous application.

Full data is not yet available for 2004. In Alexandria, as of May 2004, 850 people applied for tax exemptions. Table 1 shows that, with each passing year, more people are taking advantage of the program. In each year, more than 90 percent of applicants received either a full or partial tax exemption, or a tax deferral. In 2003, exemptions totaling \$1,658,836 were granted to 709 applicants, resulting in an average exemption of approximately \$2,340; total taxes deferred were \$7,080 and the average amount was about \$1,770.<sup>59</sup>

| <b>Table 1. Number of applicants, recipients, and people turned down for real estate tax exemptions and deferrals in 2001, 2002, and 2003, Alexandria, Virginia.</b> |             |             |             |
|--|-------------|-------------|-------------|
|  | <b>YEAR</b> |             |             |
|  | <b>2003</b> | <b>2002</b> | <b>2001</b> |
| <b>Number of applicants</b>  | 756         | 580         | 547         |
| <b>Full exemption</b>  | 625         | 162         | 178         |
| <b>Partial exemption</b>   | 84          | 374         | 337         |
| <b>Partial exemption with deferral</b>   | 4           | 38          | 31          |
| <b>Number turned down</b>  | 47          | 37          | 31          |
| <b>Deferral</b>  | 0           | 7           | 1           |

*Source:* Personal correspondence, Gary Rossi, Revenue Collections Specialist, Revenue Division, Department of Finance, City of Alexandria, May 11, 2004.

In each year, 80 to 90 percent of applicants were elderly people. The percentage of younger people with disabilities was slightly higher than the percentage of elderly people with disabilities (See Table 2).

**Table 2.** Number of applicants for real estate tax exemptions who are elderly, elderly with disabilities, and nonelderly with disabilities, Alexandria, Virginia.

|                                     | 2003 |      | 2002 |      | 2001 |      |
|-------------------------------------|------|------|------|------|------|------|
| <b>Number of applicants</b>         | 756  | 100% | 580  | 100% | 547  | 100% |
| <b>Elderly</b>                      | 677  | 90%  | 490  | 84%  | 471  | 86%  |
| <b>Elderly with disabilities</b>    | 35   | 5%   | 39   | 7%   | 32   | 6%   |
| <b>Nonelderly with disabilities</b> | 44   | 6%   | 51   | 9%   | 45   | 8%   |

*Source:* Personal correspondence, Gary Rossi, Revenue Collections Specialist, Revenue Division, Department of Finance, City of Alexandria, May 11, 2004.

For more information about Alexandria’s program, see City of Alexandria, Virginia, at [http://ci.alexandria.va.us/finance/rea\\_tax\\_relief.html](http://ci.alexandria.va.us/finance/rea_tax_relief.html).

For more information about the statewide Virginia program, see Knapp, J.L., & Kulp, S.C. (2002). *2002 Tax Rates: Virginia’s Cities, Counties, and Selected Towns (Section 3)*. 21st Annual Edition. Weldon Cooper Center for Public Service, University of Virginia, at <http://www.virginia.edu/coopercenter/vastat/taxrates2002/02section03.pdf>.

**Austin, Houston, El Paso, Tarrant County, and Dallas, Texas. The Texas Home of Your Own Coalition (Texas HOYO) was established to help people with disabilities become homeowners and maintain their housing.** Recently recognized by Fannie Mae, Texas HOYO is an excellent example of a successful home ownership coalition. The coalition unites multiple partners to help people with disabilities through every step of the home-ownership process, from counseling people with disabilities as they prepare for homeownership to helping people during the post-purchase period as they adjust to homeownership and the responsibilities that accompany it.

Texas was one of the 23 states taking part in the National HOYO Alliance.<sup>60</sup> In 1995, under the leadership of United Cerebral Palsy of Texas (UCP), a number of stakeholders united their vast knowledge of the housing industry, experience, and resources to “make the system work” for people with disabilities. The partners are committed to the program’s success and support participants in several ways:

- **Housing counseling organizations** provide prepurchase homebuyer counseling and education, budget preparation, early delinquency intervention, credit repair counseling, and post-purchase follow-up and support.
- **Realtors** help locate homes and property inspectors.
- **Lenders**<sup>61</sup> play a key role with mortgage products, down payment and closing cost assistance, and financial assistance for property rehabilitation and maintenance.
- **Disability organizations**<sup>62</sup> are involved in home assessments for accessibility, grant writing, and marketing services.

The coalition engaged state and local housing organizations to become active members and created a partnership between the coalition and the Texas Department of Housing and Community Affairs (DHCA). To date, Texas HOYO has helped more than 200 people with disabilities purchase their own homes in the urban and rural sections of Austin, Houston, El Paso, Tarrant County, and Dallas.<sup>63</sup> The majority of participants have mobility impairments (58%) and incomes at or below 50 percent of the area median income (69%).

To promote the program, HOYO uses a variety of marketing tools such as newsletters, news media, and presentations. To apply for assistance, potential participants call HOYO at an 800 number for an initial screening, attend an orientation program to learn about the homebuying process, and complete an application to determine program eligibility.

Once participants are accepted into the program, they attend a required first-time homebuyer training session and, with assistance from HOYO partners, learn how to locate a home and apply for a mortgage. Because many prospective homeowners with disabilities do not have enough money for a down payment, HOYO can cover the shortfall with a five-year forgivable loan using HOME, Community Development Block Grant funds, and affordable housing grants awarded by the Federal Home Loan Bank.

After the closing, new homeowners may receive financial assistance to make accessibility related changes. HOYO provides financial counseling, information about other programs

that provide housing assistance, and a limited amount of financial assistance. Homeowners can contact Texas HOYO with questions about their home or requests for assistance at any time.

Texas HOYO has succeeded in leveraging more than \$9 million in resources from the Texas Council for Developmental Disabilities, the Texas Department of Housing and Community Affairs, private foundations, Fannie Mae, and other lending partners. By considering itself a “homeownership program” rather than a “disability program,” HOYO has been able to extend its services beyond people with disabilities to other low-income populations in the area.

In an example provided by UCP, a couple, both in wheelchairs, bought a home in 1997 with the help of Texas HOYO. Both had personal experience living in institutions—one had been a resident of a state school for 30 years, the other had lived in a nursing home for a dozen years—so the thought that they could live independently, let alone be homeowners, never seemed within their realm of possibility.

But with \$44,000 in down payment assistance from Texas HOYO, a mortgage from HomeChoice, funds for barrier removal from the HOME program, and a Medicaid Home- and Community-Based Services (HCBS) Waiver, they were able to purchase a brand new, single-family home for \$76,000, on the \$1,120 monthly disability benefits they receive.

While the HOYO program is a labor-, time-, and resource-intensive process that requires a great deal of commitment by the coalition members, it has proved worthwhile: To date, none of the homeowners has defaulted on a mortgage.

For more information about the Texas HOYO, see Langendorf, J., Hubert, N., Eiken, S., & Schaefer, M. (2003). *Texas Home of Your Own Coalition*. Prepared for U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services (CMS), Disabled and Elderly Health Programs Division, available at <http://www.cms.hhs.gov/promisingpractices/txhoya.pdf>.

**Programs that provide incentives to incorporate accessibility features into existing or new housing stock.**

**Georgia's EasyLiving Home<sup>CM</sup> Program is a certification program that encourages builders to construct and market accessible single-family homes and townhouses.** The EasyLiving Home<sup>CM</sup> program is administered by a coalition that includes the building industry, state and local government, and accessibility advocates.<sup>64</sup> Certification by EasyLiving Home<sup>CM</sup> enables builders to advertise their homes as being easy to live in and visit for people of all ages, sizes, and physical abilities.<sup>65</sup> Homes constructed with accessibility features enable residents to remain in their own homes as they age and/or develop mobility limitations.

The first home was certified in April 2002, and 50 homes have been certified since that date.<sup>66</sup> Approximately 600 homes are now in various stages of development and construction. Certified homes range in size from 1,200 square feet to 4,500 square feet, and average 3,000 square feet. Prices range from \$90,000 to \$600,000. Twenty-five registered builders are located in Valdosta (South Georgia), Savannah, Athens, Big Canoe (North Georgia Mountains), and throughout metropolitan Atlanta. Plans are under way to expand the program to other states, with a Replication Summit planned for September 2004.

Builders qualify for EasyLiving Home<sup>CM</sup> certification by including accessibility features in the homes they build to benefit homebuyers in various ways.<sup>67</sup> For example, accessible homes have step-free entrances, wide doorways, and a bedroom, kitchen, living room, and wheelchair-friendly bathroom on the main floor, enabling social visits by friends and family with mobility limitations. Easy access for all people is stressed. For example, step-free entrances ease entry not only for people with mobility impairments but also mothers with baby strollers. Wide doorways provide access for family members with disabilities and also facilitate movement for anyone carrying bulky items or moving furniture.

The EasyLiving Home<sup>CM</sup> certification procedure includes the following steps:

- The program director and coalition partners give formal presentations to builder organizations and one-on-one presentations to builders.
- Builders who decide to register with the program pay a fee ranging from \$100 to \$1,000, depending on the number of homes they plan to certify.
- The program director offers to review the plans and suggests modifications before construction begins.
- After construction is under way, the program director conducts a home visit to check that required features are in place (e.g., measures doorways and hallways).
- Homes that meet the program's requirements are awarded a certificate and a seal that can be posted on the home.

For more information, see the EasyLiving Home<sup>CM</sup> Web site at <http://www.easylivinghome.org> and the Web site at [http://www.concretechange.org/ga\\_easy\\_living.htm](http://www.concretechange.org/ga_easy_living.htm).

**“Universal Design: Homes for the Future Today,” in Irvine, California, is a consumer education program designed to expand accessibility in single-family homes.**<sup>68</sup> Irvine's Universal Design Program stemmed from concerns among Irvine residents that, while some apartment buildings in Irvine had features designed to improve access for people with disabilities, new single-family homes being built in the city did not. The Irvine City Council appointed members to an Accessible Housing Task Force with representation from the Irvine Residents with Disabilities Advisory Board, the Irvine Senior Council, the Orange County Association of Realtors, the City of Irvine Planning Commission, the Building Industry Association, and The Irvine Company.<sup>69</sup>

The task force reviewed building requirements and cost concerns and developed a voluntary program for homebuilders to offer buyers a list of 33 accessibility features. Each participating homebuilder maintains a list containing all 33 features and indicates which of the features are available at the company's project and whether they are “standard,”

“limited,” or “optional.” The list identifies the cost, if any, to the homebuyer and at what point in the course of construction the feature must be installed. Features range from major external modifications (e.g., level entryways leading to homes) to minor changes (e.g., lever-style door handles and handheld showerheads). Sellers and buyers alike must sign an acknowledgment that the list of features was provided to the buyer.<sup>70</sup>

Plans are under way to construct at least one home with universal design features in each model home project to promote better awareness among homebuyers and encourage them to ask for these features in their new homes. A beautifully designed brochure illustrates the point that people of all ages and abilities can benefit from universal design.

The Universal Design Program is a collaborative effort<sup>71</sup> among the City of Irvine, The Irvine Company<sup>72</sup>, and the Orange County Chapter of the Building Industry Association of Southern California and was adopted by the City Council on January 25, 2000.<sup>73</sup> By 2002, 14 participating builders<sup>74</sup> had 23 new developments with homes with accessibility features ranging in size from 1,100 to 4,000 square feet and ranging in price from \$200,000 to \$900,000.<sup>75</sup> By 2004, virtually all of Irvine’s new homebuilders were participating in the voluntary program.<sup>76</sup>

Eric Tolles, Chief Building Official in Irvine’s Building and Safety Division, attributes the program’s success to Irvine’s status as a “planned urban community” and the fact that the Irvine Company owns most of the undeveloped land in Irvine and sells it to residential builders. These two factors help make it easier to obtain builder cooperation and coordinate marketing efforts.<sup>77</sup>

For more information, see the City of Irvine Web site at [http://www.cityofirvine.org/depts/cd/buildingsafety/accessibility\\_universal\\_design.asp](http://www.cityofirvine.org/depts/cd/buildingsafety/accessibility_universal_design.asp).





## **Chapter 3: Ensure Accessible, Affordable, Reliable, Safe Transportation**

Terry Szold, a land use planning consultant and adjunct associate professor in the Department of Urban Studies and Planning at the Massachusetts Institute of Technology, lives in Andover, Massachusetts, and needs to travel out of town occasionally for work and professional meetings. Szold has relied on a scooter to get around for the past eight years and owns a van with a lift that accommodates the scooter. She generally is able to get where she needs to go. But when she travels outside the immediate surroundings of her home and work, she often encounters barriers. A recent business trip to Washington, D.C., was a case in point.

Professor Szold took Amtrak's Acela Express train from Boston to Washington, D.C., and gave it high marks for accessibility. She also praised Washington's subway system. As long as she traveled the main subway route, access was good. But during her stay, Szold also had to travel to meetings located beyond the immediate downtown area, and the only way to get where she needed to go was by taxi. She was shocked and dismayed to find that there is not a single wheelchair-accessible taxi in the nation's capital. Luckily her husband, who accompanied her on this trip, was available to help her get into a regular taxi. He then dismantled her scooter to fit inside the car. If she had traveled alone, Professor Szold could not have managed these tasks on her own.

When relating this story, Szold reveals her anger about the challenges she faced on this business trip. She makes the point that unavailable or inaccessible transportation is not simply an annoyance and inconvenience for people with disabilities; "it is something that can impede people's career advancement," she says. Whether it's a train, a subway, a taxi, or any other vehicle, accessible transportation is not just a means of getting from Point A to Point B, it is a means of accessing work opportunities, medical care, goods and services, and civic and social activities. For people with disabilities, the availability of transportation that accommodates their mobility needs takes on even greater significance because it promotes their independence, self-sufficiency, and full participation in community life.

According to the 2003 National Transportation Availability and Use Survey,<sup>78</sup> about one in four individuals with disabilities needs help from another person and/or some sort of assistive equipment, such as a cane, walker, or wheelchair, to travel outside the home.<sup>79</sup> Nearly one in eight people with disabilities, or about 6 million, have difficulty getting the transportation they need because public transportation in their 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, among other reasons.<sup>80</sup>

The survey also found that more than 3.5 million people in the United States never leave their homes. More than half of the homebound—1.9 million—are people with disabilities. Of these nearly 2 million people, 560,000 indicated that they never leave home because of transportation difficulties.<sup>81</sup> Access to transportation also was identified as a major issue by participants in the focus group. Participants who use wheelchairs and paratransit<sup>82</sup> services recalled times when at the end of a work day they were left downtown on their own with no way of getting home. Sometimes the wait was five hours or longer, with no central phone number to call for information or assistance. Focus group participants who used public transportation for their day-to-day travel talked about the barriers they sometimes face, such as bus stops where the space is so narrow they cannot maneuver their wheelchairs, obstructions from nearby construction sites and, in the winter months, piled up snow and ice.

As a result of ADA of 1990, state and local governments must give people with disabilities an equal opportunity to benefit from all government programs, services, and activities, including transportation. The transportation provisions of ADA's Title II cover public transportation services, such as city buses, public rail transit, subways, commuter rails, and Amtrak.<sup>83</sup> Public transportation authorities may not discriminate against people with disabilities and must comply with accessibility standards in newly purchased or leased vehicles and in vehicles that have been remanufactured.<sup>84</sup> Under ADA, transit operators also must provide paratransit services along existing fixed-route bus or rail systems, unless it would result in an "undue burden." ADA does not require that all taxis be wheelchair accessible if a city provides alternative transportation opportunities for people with disabilities. But in big cities like Washington, D.C., or New York, where, as Terence Moakley, associate executive director of the United Spinal Association says,

people “think of taxis as part of [the] basic transportation system,” one would expect to see more accessible cabs than there actually are. In New York City, for example, only 5 out of 12,187 yellow cabs on the street today are wheelchair accessible. Some U.S. cities, such as those profiled later in the chapter, are working on expanding fleets of accessible taxis, but these efforts pale in comparison with those of London, England, where 100 percent of taxis are wheelchair accessible.<sup>85</sup>

Nationally, compliance with ADA transportation provisions is still a work in progress. Since these provisions went into effect, for example, the Federal Transit Administration (FTA) and the nation’s transit operators have been working to ensure that buses used in every community’s fixed-route bus system are 100 percent lift or ramp equipped by the year 2007. By the end of 2001, 83 percent of transit buses were ADA compliant, compared with 35 percent in 1990.<sup>86</sup> In many communities, bus fleets are already 100 percent ADA compliant for people with mobility impairments, and, in some of these communities, transit authorities have gone the extra mile to make the transit system disability friendly. In Austin, Texas, for example, buses have automated audible systems that announce upcoming bus stops, and bus stop signs are in Braille.

Providing accessible, affordable, reliable, and safe transportation is such an enormous challenge that some states and counties have been thinking “systemically,” trying to coordinate all the disparate transportation services and funding streams to create more efficient, cost-effective, and universally accessible transit systems. Realizing that lack of coordination is largely due to the fact that 62 different federal programs fund transportation, not to mention the proportion of state and local taxes earmarked for transportation, several federal agencies, including the FTA and the Departments of Health and Human Services, Labor, and Education, have launched “United We Ride,” a national five-year initiative to break down the barriers within human service transportation programs and encourage local partnerships to improve transportation services.<sup>87</sup> One of the components of this initiative is the *Framework for Action: Building a Fully Coordinated Transportation System*, a comprehensive evaluation and planning tool to help state and community leaders, and agencies involved in human service transportation and transit service, along with their stakeholders, improve or start coordinated transportation systems.<sup>88, 89</sup>

A number of states and counties profiled later in this chapter—including the State of Florida; Broward County, Florida; counties in Central Virginia; and Sweetwater County, Wyoming—have been working for some time to increase the options and availability of accessible transportation for people with disabilities through coordinated transportation services.

In his New Freedom Initiative (NFI), President Bush called for expanded opportunities for people with disabilities, stating that “every American should have the opportunity to participate fully in society and engage in productive work. Unfortunately, millions of Americans with disabilities are locked out of the workplace because they are denied the tools and access necessary for success.”<sup>90</sup> Echoing Terry Szold’s story, the NFI 2002 progress report states that “inadequate transportation inhibits employment for all people, but is an even greater barrier to people with disabilities.”<sup>91</sup> The Job Access and Reverse Commute (JARC) Program addresses this issue through grants to state and local agencies to provide new employment-related transportation services for low-income persons, including people with disabilities. Since the inception of the program, the Federal Government has funded more than 200 such programs in 44 states.

Several examples of state- and county-coordinated transportation efforts, JARC Program grantees, and cities that are enhancing their on-demand transportation options by expanding their accessible taxi fleets are profiled below. These programs are followed by examples of dedicated community-based organizations (CBOs) and individuals who initiated bottom-up approaches to addressing transportation issues and are influencing community decisionmakers to improve transportation options for people with disabilities.

## **Coordinated Transportation Systems**

- **The State of Florida has been working since 1979 to expand transportation services through the Florida Coordinated Community Transportation Program.<sup>92</sup>**

In 1979, the Florida Legislature enacted a law that requires coordination among programs that receive local, state, and federal funds to provide or purchase transportation for persons who were collectively termed “transportation disadvantaged (TD).”<sup>93</sup> The program was reenacted in 1989. The 1989 act created the Florida Commission for the Transportation Disadvantaged (CTD), an

independent commission housed administratively within the Florida Department of Transportation (DOT). The CTD enhanced local participation in the planning and delivery of coordinated transportation services by creating local coordinating boards (LCBs) and community transportation coordinators (CTCs).

In accordance with the statute, the CTD contracts with CTCs that serve each of Florida's 67 counties. These coordinators assist in planning and coordinating transportation services for the TD.

**Funding:** Florida has created a Transportation Disadvantaged Trust Fund (the TD Fund) to maintain a steady state funding source that can be used to match various federal grants and to purchase transportation for nonsponsored TD persons. The TD Fund revenues of approximately \$20 million annually are generated from a \$1.50 additional charge on each vehicle registration renewal. In addition, the state has a voluntary contribution program called "Put Your Dollar to Work." A check box on the vehicle registration form permits people to submit an additional, voluntary contribution of \$1.00 to the Fund. The TD Fund pays for transportation for persons whose trips are not sponsored by other programs. Other major funding sources include the Agency for Health Care Administration, DOT, Department of Children and Families, and other local funds.

**Service:** Service patterns are determined on a county-by-county basis by LCBs, who provide oversight for the CTCs. Transportation is provided by more than 460 qualified providers statewide, including public transit operators, taxi companies, human service agencies, and volunteers. Florida's coordinated transportation services are primarily intended for people who not able to transport themselves, including clients of human service agencies and people who qualify as TD. Clients call their service agency, which then arranges the necessary trips. Individuals who are not agency clients but who are TD schedule trips through the CTC or a service provider designated by the CTC. In fiscal year (FY) 2003, more than 53 million trips were provided through the coordinated transportation network, with approximately 60 percent of those trips provided to people with disabilities.

**Benefits:** The state-directed coordination of transportation services has many advantages:

- The number of trips taken through the system grew from 1.5 million in 1985 to 36 million in 1998 to more than 53 million in 2003.
- A recent independent assessment conducted by the University of Florida Bureau of Economic and Business Research showed that the current coordinated TD program has saved the Florida Agency for Health Care Administration as much as \$22 million dollars in Medicaid nonemergency transportation costs during FY 2002.
- Some of the savings were used to expand transportation services by providing more trips and serving more clients.
- The coordination effort also increased state and local investments in transportation for persons who were not previously eligible for specialized services.
- In February 2004, the U.S. DOT awarded the Florida CTD with one of five United We Ride State Leadership Awards, recognizing their achievements in improving transportation for people with disabilities, older adults, and low-income families, while improving cost effectiveness.

For more information, contact

John P. Irvine

Public Relations Manager

Commission for the Transportation Disadvantaged

605 Suwannee Street, MS-49

Tallahassee, FL 32399-0450

Helpline: (800) 983-2435

Email: [john.irvine@dot.state.fl.us](mailto:john.irvine@dot.state.fl.us)

- **Broward County, Florida, Transportation Options (TOPS)<sup>94</sup> is an example of coordination at the local level under the leadership of the Florida CTD.**

Broward County introduced the new coordinated, multiprovider, paratransit service—TOPS—in December 1996. Services are administered by the local transit authority and provided by both for-profit and nonprofit agencies.

**Funding:** During the fiscal year ending June 30, 2004, more than 67 percent of the funds for the TOPS program came from monies that the county had allocated to pay for ADA paratransit costs; 12 percent came from the Florida CTD and an additional 21 percent came from the state Medicaid program.

**Service:** TOPS provides paratransit service for clients of for-profit and nonprofit agencies and serves as ADA's complementary paratransit provider. Broward County Transit (BCT) contracts with seven service providers to take reservations, schedule trips, and maintain contacts with riders. Trips are provided in vans and sedans, with more than 300 vehicles in use. The service providers are supplied with computer hardware and software linking them to BCT's centralized computer system. All registration, reservations, scheduling, route building, and billing functions are processed through the system. The services are provided on a prescheduled, routed, shared-ride basis. In accordance with ADA, services mirror the hours of operation of the public fixed-route transit service. The service area now covers all 437 square miles of Broward County, and provides service within  $\frac{3}{4}$  of a mile from an established Broward County bus route in neighboring counties. Riders call their designated service provider to schedule a ride. They are picked up within a 30-minute window (15 minutes before or 15 minutes after the scheduled pick-up time). It is up to the provider to determine whether same-day service will be possible. Riders must pay a fare of \$2 for each one-way trip. As of June 2004, more than 31,000 people were enrolled in the TOPS program. More than 1.3 million trips are made on the system annually.

**Eligibility:** Riders must register with TOPS for paratransit services. They must be ADA eligible, human services agency clients, or eligible for subsidized trips provided through Florida CTD program. To qualify for ADA paratransit, the rider must submit a detailed, multipage application with a doctor's signature and have an in-person evaluation. The application process takes three weeks, and eligibility is usually granted for a three-year period.<sup>95</sup>

**Benefits:**

- Since 1997, the number of trips provided by TOPS has more than doubled.

- Service quality has improved through mandatory training sessions of paratransit providers and random quality of service surveys.
- All trip requests are accommodated with a “zero trip denial” policy.
- Riders have an option to change their service provider, if not satisfied, through the Rider’s Choice Program.
- In 1998, the American Public Transit Association named TOPS the best paratransit system in the country.
- In 2003, the TOPS program won the Community Transportation Association of America’s (CTAA) President’s Award. Also in 2003, the Florida CTD named TOPS the Urban Community Transportation Coordinator of the Year.

For more information, contact  
 Transportation Option (TOPS)  
 3201 W. Copans Road  
 Pompano Beach, FL 33069  
 Information Line: (954) 357-6794  
 TTY: (954) 357-8330  
 Web: <http://www.broward.org/tpi02700.htm>

- **The JAUNT, Inc. Regional Public Transit Agency<sup>96</sup> of Central Virginia was formed in 1975 to meet the transportation needs of area human service agencies. Today, JAUNT serves as a rural service provider, a leader in commuter transportation, a coordinated human service agency transporter, and an urban paratransit provider. JAUNT provides services to the citizens of Albermarle, Fluvanna, Louisa, and Nelson Counties and the City of Charlottesville with a fleet of more than 70 vehicles.**

**Funding:** JAUNT, Inc. is a public corporation owned by the local governments that it serves. JAUNT uses federal and local funding to supplement fares and agency payments. Local governments provide 30 percent of its revenue, the Commonwealth of Virginia provides 14 percent, and federal sources constitute 25 percent. Agency contracts for service, such as with



Medicaid, account for another 13 percent and Welfare-to-Work grants provide an additional 10 percent of income. Highly supplemented fares make up only 8 percent of JAUNT's revenues. JAUNT's operating and administrative costs for the fiscal year ending June 2004 were \$3.6 million.

**Service:** The system maintains several weekday commuter routes that give residents job access in Charlottesville and Albermarle. JAUNT provides ADA paratransit service for Charlottesville's urban public transit system, which offers fixed-route service within the city. Service is available between 6:30 a.m. and midnight, Monday through Saturday, and between 7:00 a.m. and 10:00 p.m. on Sunday. Riders must call in their trip requests at least 24 hours in advance, although 48 to 72 hours notice is preferred. If previously registered, a traveling companion or a personal care assistant may ride for free. Guide dogs and other service animals are allowed to accompany the rider if indicated on the application. JAUNT provides 1,200 trips every day. Approximately three-quarters of these trips are for people with a disability.

JAUNT continues to be the provider of choice for human service agencies in Central Virginia. Agencies can make arrangements to have individuals and/or groups of their clients transported. During FY 2004, JAUNT provided almost 90,000 trips for agency-sponsored passengers traveling to medical appointments, supported employment, nutrition programs, and other beneficial activities. Agencies pay an hourly fee for this service.

**Eligibility:** Anyone may ride JAUNT, but reduced fares are available for people with disabilities after their applications are approved. Visitors from other cities who are eligible under ADA criteria are welcome to use JAUNT during visits up to 21 days.

**Benefits:**

- JAUNT provides transportation services that were not previously available or affordable to persons living in rural areas.
- Riders enjoy a substantial cost savings. Fares for passengers with disabilities range from \$1.50 to \$5.25, depending on the length of the trip and whether or not the route is fixed.

- Coordinated transportation services have saved money for consumers and public agencies in Central Virginia, compared to services purchased through private providers.

For more information, contact

Donna Shaunesey

Executive Director

JAUNT, Inc.

104 Keystone Place

Charlottesville, VA 22902

Phone: (434) 296-3184

Email: [info@ridejaunt.org](mailto:info@ridejaunt.org)

Web: <http://www.ridejaunt.org/>

- **The Sweetwater County, Wyoming<sup>97</sup> public transportation's transit authority (STAR) was created in 1989 and replaced a number of health and human services agency-based transportation services to form a coordinated public transportation system. STAR provides transportation to the general public and to agencies on a contractual basis, and serves the sparsely populated 10,400 square mile area of Sweetwater County in southwest Wyoming.**

**Funding:** STAR has funding from more than 10 different sources, including state agencies, employers, and community organizations. STAR is the fiscal agent for the county's transportation funds and operates with an annual budget of approximately \$500,000.

**Service:** The transit agency uses a fleet of 10 vehicles to provide door-to-door service with no fixed-route operations. All buses and vans are equipped with wheelchair lifts. STAR uses a central dispatcher to arrange approximately 4,000 rides per month. About 30 percent of all rides are provided to people with disabilities, and 25 percent to the elderly. The system is computerized and maintains detailed records on every trip taken. Before 1995, all rides were free. Fares are now \$2.00 for each one-way ride. More than 90 percent of riders have a regularly scheduled trip, and the remainder book rides a day or two ahead. The first time someone calls for

a ride, he or she goes through a three-minute interview to be registered in the system's database. STAR accepts ride requests for all trip purposes, including going to schools, libraries, movies, and other activities. While riders must generally call 24 hours in advance of the time they need to travel, approximately 10 percent of STAR's rides are provided on a same-day basis. STAR contracts with human services agencies to provide transportation for clients and bills for trips according to agency-specific billing rates.

**Eligibility:** STAR is a public transportation system, providing service to the general public and clients of human service agencies.

**Benefits:**

- STAR has expanded both transportation service and the pool of people who use it. Trips that formerly were provided only to agency clients now are open to the general public. Ridership has increased from 20,000 total trips per year before the creation of STAR to 46,759 total trips during FY 2003/04.
- Service is available Monday through Friday from 7:00 a.m. to 5:00 p.m. Some after-hours trips are available by special arrangement.
- By careful coordination and dispatch, the system is able to provide door-to-door services at a low cost of about \$7.00 per trip and an average passenger-per-vehicle-hour of 4 to 6 passengers.
- A 1997 U.S. DOT study determined that, through coordination, Sweetwater County and its municipalities save more than \$1.6 million per year, or \$3.50 in benefits for every \$1.00 spent on STAR.
- The STAR model has been recognized nationally for efficient, affordable transportation service. It is one of many being implemented across the country focused on coordinating transportation services to provide more rides with existing funds.

For more information, contact

Judy Owens

Director

Sweetwater County Transit Authority (STAR)

1471 Dewar Drive, Suite 123

Rock Springs, WY 82901

Phone: (307) 382-7827

Fax: (307) 352-6896

Email: starbus@fascination.com

### **Job Access and Reverse Commute (JARC) Programs<sup>98</sup>**

- **Allegan County, Michigan**, used its JARC grant,<sup>99</sup> with matching funds from the Michigan DOT and the Family Independence Agency, to start the Allegan County Transportation (ACT). With additional operating dollars provided by fee-for-service contracts with Allegan County Community Mental Health (CMH) and Work First, it offers workers transportation to jobs and other destinations Monday through Friday from 5:30 a.m. until midnight.

ACT rolled out its Job Access service in 2000, operating with two vehicles donated by the CMH and Allegan County Resource Development Committee. Currently, the system has 12 employees and runs 12 vehicles, 6 of which are lift-equipped. ACT provides demand-response and advance-reservation service Monday through Friday from 5:30 a.m. to midnight, with limited additional service for those who work on weekends.

In FY 2002, the service logged almost 320,000 miles and provided more than 20,000 trips. About 65 percent of riders are people with disabilities, most using the service to reach jobs both in and out of the county. These jobs are largely in the service industry at hotels, restaurants, discount retail stores, gas stations, and other locations.

For more information, contact

Dan Wedge

Director

Allegan County Transportation

3255 122nd Avenue  
Allegan, MI 49010  
Phone: (269) 686-4529  
Fax: (269) 673-4172  
Email: [dwedge@allegancounty.org](mailto:dwedge@allegancounty.org)

- **A Santa Clara, California,** public/private partnership formed the Guaranteed Ride Program (GRP) in 1999 to offer CalWORKS (California's Temporary Assistance for Needy Families program) participants a short-term transportation service should they need a back-up ride. It provides participants up to 48 rides per person to work-related destinations. JARC funds<sup>100</sup> support this service, along with CalWORKS funds from the county Department of Social Services. GRP provides door-to-door service 24 hours a day, seven days a week.

GRP is operated by a private nonprofit agency called OUTREACH.<sup>101</sup> OUTREACH is the paratransit broker for the Santa Clara Valley Transportation Authority (VTA). As the countywide broker of accessible transportation services, OUTREACH provides rides to a large portion of county residents with disabilities. Most of these riders are eligible for the county's ADA paratransit service that complements the Santa Clara VTA fixed-route bus system. People with disabilities who enroll in CalWORKS or other training and support programs for low-income people may be eligible to take advantage of the OUTREACH Guaranteed Ride Program. Paratransit riders who typically pay \$3.00 each way for a trip have the cost of the rides subsidized while using this JARC-sponsored service to get to training, interviews, and jobs.

For more information, contact  
Kathryn B. Heatley  
Chief Executive Officer  
OUTREACH  
926 Rock Avenue, Suite 10  
San Jose, CA 95131

Phone: (408) 436-2865, extension 290

Email: [katieh@outreach1.org](mailto:katieh@outreach1.org)

- **The Rhode Island Public Transit Authority (RIPTA)** used its JARC funds<sup>102</sup> to implement five flexible service demonstration programs in Rhode Island's low-density suburban and rural communities that provide people with disabilities with a reliable zoned-based transportation system. A sixth program has been added with funding provided by the University of Rhode Island. Called Flex Service, this program takes riders to work and other destinations within a defined zone. Passengers can travel outside the zone by using Flex Service and then transferring to RIPTA's fixed routes or paratransit services. The transfer costs riders an additional ten cents. RIPTA's Flex Service is providing more than 160 trips to work and back per month to people with disabilities (trips to work and back for people with disabilities are prioritized and, therefore, tallied; for trips that are not work-related, however, riders are not asked whether they have disabilities). In addition, approximately 80 trips per month are provided to people using wheelchairs.

The need for Flex Service became apparent when a statewide survey revealed a large unmet need for work-related transportation for residents with disabilities. Without Flex Service, individuals with disabilities would pay one-third or more of their gross salaries on taxis to get to and from work. Other individuals would have to rely on rides from family members. Those who could not get transportation would likely remain unemployed.

For more information, contact

Anne LeClerc

Principal Planner

Rhode Island Public Transit Authority

265 Melrose Street

Providence, RI 02907

Phone: (401) 781-9400, extension 135

Email: [aleclerc@ripta.com](mailto:aleclerc@ripta.com)

Web: <http://www.ripta.com/schedules/index.php/section/60>

## **Demand-Response Transit Options: Expansion of Accessible Taxis<sup>103</sup>**

- In **Chicago, Illinois**, the city government provided funds to equip more than 50 new or used minivans with side door ramps and securement systems, and developed and offered special training for drivers. Taxicab companies that have wheelchair-accessible cabs in their fleets have agreed to participate in a “central dispatch system,” which has a dedicated toll-free telephone number that passengers can use to request service to provide better and safer taxi transportation to people with disabilities. The city passed an ordinance requiring that every fleet of 15 or more taxicabs have at least one accessible cab in service. The city has also made reimbursements available to cab companies to defray the differential between the cost of an accessible, ramp-equipped van and the cost of the usual sedan. The Chicago Transit Authority also has two separate taxi voucher programs that provide people with disabilities trips in accessible taxis.
- A few years ago, when 300 new taxi medallions<sup>104</sup> were made available in **San Francisco, California**, 50 of them were specifically slated for wheelchair-accessible vehicles. As of 2004, 75 of San Francisco’s taxi medallions were set aside for accessible vehicles.
- In **Fort Lauderdale, Florida**, the owner of the Yellow Cab company incorporated accessible taxicabs into his fleet nine years ago, because he had a friend who used a wheelchair and had trouble getting a cab. Currently, approximately 20 of the 500 taxicabs in his fleet are accessible.
- **Los Angeles, California**, requires that 2 percent of taxi company fleets consist of accessible vehicles. Currently, 127 of the city’s 1,931 taxicabs are accessible. In **Las Vegas, Nevada**, 2 vehicles in each of its 14 fleets need to be accessible. There are 28 accessible cabs out of 1,100 in the city.
- In **Long Beach, California**, the transit authority purchased 12 new ramped, wheelchair-accessible, 5- and 6-passenger vans in 1999 and leased them to Yellow Cab of Long Beach for a nominal monthly fee, provided Yellow Cab operates the vehicles as part of its regular 24-hour taxicab service.

## **Tax Support for Improved Transit**

- **In a successful effort led by disability advocates, the faith community, and other CBOs, residents of six cities in Kent County, Michigan, passed a millage<sup>105</sup> increase to fund expanded transportation services that benefit many segments of the population.**

David Bulkowski, J.D., executive director of Disability Advocates of Kent County, Grand Rapids, Michigan, calls October 1996, the “low point” in Kent County’s recent transportation history. Although the creation of a Transit Authority to address the county’s public transportation issues was supported by disability advocates and other groups in the county, the County Commission voted that month against it. Disappointed but not defeated, the disability community held a People’s Transportation Forum and Barbecue to raise awareness about transportation issues in the community and brainstorm ways to make the system better. Thus began a well-organized, multiyear grassroots effort to expand and improve transportation service in the county.

Grand Rapids, the county’s seat and urban center, is often called the “city of churches,” because of its many houses of worship, as well as the presence of Aquinas College and Calvin College, so it was natural for Bulkowski, who had spent 11 years in a Catholic seminary himself, to turn to his friends in the faith community for support in pushing forward the transportation agenda. In the spring of 1999, Faith in Motion—“a coalition of religious organizations working for better public transportation”—got started. One of the first events the group held was a prayer service across the street from a Grand Rapids bus station at 6 p.m.—the hour when public bus service stopped for the day, resuming at 6 a.m. the next day. According to Bulkowski, there was “No evening service, and can you believe that in the ‘city of churches’ there was no Sunday bus service either?” The ministers, rabbis, seniors, business owners, people with disabilities, and other community members attending the prayer service wanted to send a message to the city government that transportation is not only a means for moving people from one place to another but also “an engine for economic prosperity that benefits everyone,” says Bulkowski.

Friends of Transit, a broad-based community group, raised \$100,000, mostly from church-based donations solicited by Faith in Motion, to support lobbying efforts. In the summer of 1999,



mayors from six cities in the county, who were in favor of expanded transportation service, proposed raising the millage for transportation from 0.3 mills (the figure at that time) to 0.75 mills to support the expansion. The proposal was put to a vote in the spring of 2000 and it passed in four of the six cities—“a major accomplishment given that this area is very conservative in terms of taxation,” says Bulkowski. The bus fleet serving the area was already fully accessible, but, says Bulkowski, the new, expanded evening and Sunday service in the four cities opened up a whole new world to people with disabilities, older people, and others in the community. By the fall of that year, public transportation ridership in Grand Rapids and surrounding cities was outpacing national averages.

The millage renewal was slated for 2003. Because of decreased state funding for transportation, some advocates argued that to keep service where it was, or improve it slightly, a raise would be necessary. Rallies were held at meetings of the Rapid Board, the public transportation authority in the greater Grand Rapids area, asking the Board to propose increasing the millage to 1.0 mills. When all was said and done, an increase to 0.95 mills was put on the ballot, and this time it passed in all six cities.

Not content to rest on their laurels, transportation advocates in the Grand Rapids area, which now include Concerned Citizens for Improved Transit (a coalition of disability advocates and organizations for the cognitively impaired, visually impaired, and others) and the Emergency Need Task Force Transportation Sub-Committee (senior advocates, health care, and other services providers), have set their sights on other needed improvements. Bulkowski explains:

A continuing issue is that buses drop people off in areas where there are no curbs, and we've been addressing this on an individual-by-individual basis. We got these new electronic fare boxes that use fare cards with magnetic strips, but they are not accessible for people with visual and cognitive impairments because they either cannot see or cannot understand how much fare is left on their cards. We're also working on the county to make transportation a county-wide issue rather than approaching it city by city.

If their past success is any indication, these active CBOs will eventually solve these remaining problems, too.

For more information contact  
David Bulkowski  
Disability Advocates of Kent County  
3600 Camelot Drive SE  
Grand Rapids, MI 49546  
(616) 949-1100 Phone  
(616) 949-1100 TTY  
Email: dave.b@disabilityadvocates.us

### **Advanced Technology to Improve the “Navigability” of Public Transit**

- **Inspired by a California inventor, Charlotte, North Carolina, is pilot-testing an innovative program with portable devices that use global positioning system (GPS) satellite technology to empower people with visual impairments to better navigate the city’s public transportation system.**

Michael May, blind since he was three years old, had more than just transportation in mind when he spearheaded the development of the first handheld devices that use GPS satellite technology to make location information readily available to the blind. According to May, “Not having the information you need to get around is what determines your blindness. Traditionally, the way blind people got direction was ‘walk five blocks, turn left, walk three blocks,’” says May, “But what about what’s on the way? If you don’t know about a restaurant, you can’t go there. Accessibility is about having options.”

May founded the Sendero Group (<http://www.gps-talk.com/>) in 1994 with four other blind and visually impaired professionals. The BrailleNote GPS and talking GPS systems that they produce and/or distribute provide blind people with access to a vast database of location information for businesses and points-of-interest in towns and cities across the globe. Those with the devices can also input “user points” containing information relevant to them personally. Many user points, such as guide dog schools and physical obstacles, may be particularly relevant to people with visual impairments, and these user points can be downloaded without cost by anyone who has a GPS system. In 2000, May regained some vision after surgery, but he explains, “The GPS gives

me more access than what I can get from my low vision. I still can't read a sign or see places that are far away.”

May and his team have partnered with the Charlotte Area Transit Service (CATS) and the Metrolina Association for the Blind (MAB) to launch the first system that provides comprehensive bus-stop location and route information tailored specifically for the blind and severely visually impaired. Laura Park-Leach, vice president and director of Personal Adjustment & Rehabilitation for the Metrolina Association for the Blind, explains that blind people need to know more than just the location of bus stops for the public transit system to be truly accessible to them. “They need to know if the bus stop will have a shelter, a bench, or just a pole. Will there be a large tree or a hill nearby? They need to know where the bus goes and when it will come. They also need to know what to expect when they get off of the bus.”

The transfer of bus information to GPS users is just one part of a larger effort by CAT and MAB to get relevant information to the blind and visually impaired. Park-Leach, a mobility specialist, explains:

The GPS system appeals to youth and technically savvy people, but we also want to reach the broadest population possible. That's why the same type of information will be available through CATS customer service. People can call in from home or from their cell phones, and customer service agents will be trained to know what information visually impaired people need and why.

Data also will be available on the Web so that visually impaired customers can plan trips in advance. MAB is in the process of obtaining digital photos of each bus stop in Charlotte so that mobility specialists can examine them to identify relevant landmarks and obstacles. The organizations are advising the city on how to collect more relevant data in the future.

When detailed bus route information is made available, The BrailleNote GPS and talking GPS systems can be used in two ways. For example, if users want to find a restaurant on their way to work, they can request a search that gives them a list of all restaurants, say, 300 yards away from their bus route. Alternately, users can request a search for a restaurant in the city. They then

choose a restaurant and set it as their destination. The system calculates the best route to the restaurant and directs users to the nearest bus stop. The system also provides a wealth of information about each bus stop area and informs users when to expect the next bus. They also can access information about other businesses or landmarks on the way to the restaurant.

Park-Leach explains that the pilot project in Charlotte has been extremely inexpensive, “The city already collects this data. It is just a matter of transferring it, which does not cost much at all.” In fact, Park-Leach says, this project could potentially save the city money. “Although there will always be a need for paratransit services, many people will shift to using the less expensive fixed-route system if they have a truly accessible system,” says Park-Leach, “People will have more freedom, but they need security, especially if they are going somewhere that they don’t know.”

May is working on a similar project with officials from Portland, Oregon, and many other cities have expressed serious interest. He explains:

Access is about infrastructure and what people can do for us, but it’s also about our own empowerment. Access to information enriches the travel experience. It’s like comparing a two-wheel drive car to a four-wheel drive car. In a two-wheel drive car you stay on the main road and don’t get into trouble. In a four-wheel drive car you get off the main road. You may get stuck, but part of the adventure is getting around on your own.



**Figure 2.** Woman using the BrailleNote GPS system while in transit.



**Figure 3.** Graphic of the BrailleNote GPS v3.

*Photographs, courtesy of Mike May, are available on the Sendero Group's Web site at <http://www.gps-talk.com>.*



## **Chapter 4: Adjust the Physical Environment for Inclusiveness and Accessibility**

In 1996, Michele Ohmes, who is Kansas City, Missouri's, ADA/Disability Specialist, gave her first presentation to the American Public Works Association (APWA) at their International Public Works Congress in Minneapolis. That evening, the Kansas City Metro Chapter of the APWA arranged a dinner at a local riverfront restaurant. When Ohmes and her boss arrived at the building where the restaurant was located, they found that the building entrance was up a flight of stairs—an obstacle for Ohmes, who uses a wheelchair. So they walked around the building in search of an entrance with a ramp that Ohmes could use. They finally found a way to enter the building, only to face another obstruction—several sets of steps that needed to be negotiated to reach the restaurant entrance. Short of leaving, Ohmes had no other option—she had to crawl up the stairs while her colleagues carried her chair.

While Ohmes deals with such situations daily, the experience made an enormous impression on the APWA leadership, who heard the story from Ohmes' colleagues. Those who arranged the dinner realized they had made a mistake in not checking out the restaurant for accessibility beforehand, and, as a result of this incident, the APWA has made accessibility its priority in planning all subsequent major events. Reflecting on the incident, Ohmes says she believes that the world is full of good people who simply don't understand the importance of accessibility for people with disabilities until they have a personal experience with it, as her colleagues had in Minneapolis. But with training, she says, it is possible to raise their awareness and “change the world.”

A simple act that most of us take for granted—like entering a building or going out to dinner—can become quite complicated if you use a wheelchair or have other disabilities that affect mobility. Shopping in a supermarket, attending a sporting event, going to a doctor's office, traveling out of town, renting a car, staying in a hotel—in short, doing many ordinary, everyday things can become fraught with frustration when “public accommodations” have not successfully removed barriers to use by people with disabilities.

Access to civic life by people with disabilities is one fundamental goal of ADA, which was passed in 1990. Title II of ADA requires state and local governments to make their programs and services accessible to people with disabilities. This includes providing physical access at government facilities, programs, and events. It also includes making policy changes to ensure that all people with disabilities can take part in, and benefit from, the programs and services of state and local governments. And it ensures effective communication through the provision of necessary auxiliary aids and services, such as interpreters or assistive listening devices, to people with disabilities to facilitate their participation in public events and meetings. Title III of ADA addresses access to privately owned businesses, such as stores, restaurants, hotels, theaters, museums, schools, and recreational facilities. Under this section of the law, public accommodations that provide goods and services may not discriminate against individuals with disabilities. The U.S. Department of Justice is responsible for enforcing these two sections of ADA.<sup>106</sup>

To be sure, since the passage of ADA, noticeable accommodations have been made in communities large and small to improve access for people with disabilities, although perhaps not as many or as quickly as some advocates would like. Judging by the steady stream of ADA-related complaints received by the Department of Justice's Disability Rights Section (DRS)<sup>107</sup> and the long list of settlement agreements that the Department has negotiated with communities throughout the country, many communities do not make access-related changes until (1) someone lodges a complaint, (2) the Department gets involved, and (3) a remedy is negotiated and then implemented.

In 1999, for example, the Department of Justice reached a settlement with the City of Toledo, Ohio, in which the city agreed to remove barriers and relocate activities throughout its city government, including the municipal courthouse, district and neighborhood police stations, a market-outlet complex, fire stations, parking garages, museums, community and social services, the city's parks and recreation centers, the health department, and other city administrative buildings. Building on that settlement, then-Attorney General Janet Reno asked the DRS to ensure that other cities across the United States address these important issues as well. In response, the DRS established "Project Civic Access"<sup>108</sup> and began similar reviews of other local



and state governments. The DRS selected at least one city in each of 50 states to visit and review, as well as two departments in the District of Columbia and two communities in Puerto Rico, and developed technical assistance materials so that the communities could immediately begin to come into full compliance with ADA requirements. These on-site investigations have concluded in the chosen communities and settlement agreements with all of the communities were reached by October 2004.

Although the scope of this effort was limited, the DRS quickly translated its experience with the chosen communities into lessons learned and technical assistance materials for other communities. Among these technical assistance materials is a useful manual that identifies common misconceptions and problems found in local governments that must comply with Title II of ADA.<sup>109</sup> According to the DRS, city governments—

- May (wrongly) believe that their existing programs and facilities are protected by a “grandfather” clause from having to comply with the requirements of Title II of ADA. Small municipalities may (wrongly) believe that they are exempt from complying with Title II because of their size.
- Often fail to ensure that the whole range of the city’s services, municipal buildings, and programs meet Title II’s program access requirements.
- May (wrongly) believe that they have no duty to make changes to historically significant buildings and facilities to improve accessibility for people with disabilities.
- Often do not provide necessary curb ramps to ensure that people with disabilities can travel throughout the city in a safe and convenient manner.
- Often fail to provide qualified interpreters or assistive listening devices for individuals who are deaf or hard of hearing at public events or meetings. In addition, city governments often fail to provide materials in alternate formats (Braille, large print, or audio cassettes) to individuals who are blind or have low vision.
- May fail to consider reasonable modifications to local laws, ordinances, and regulations that would avoid discrimination against individuals with disabilities.

- Do not provide direct and equal access to 911 systems, or similar emergency response systems, for individuals who are deaf or hard of hearing and use TTYs (TDDs or text telephones) or computer modems.
- Often fail to modify policies, practices, or procedures when dealing with people with disabilities in law enforcement settings—including citizen interaction, detention, and arrest procedures.

Private businesses have much to learn about increasing accessibility as well. Fortunately, ample resources are available to inform and guide the business community about complying with accessibility regulations, if they are willing to do so.<sup>110</sup> In many cities, including some of those profiled below, disability advocates and/or city agencies have developed and disseminated their own accessibility standards, which often go beyond ADA guidelines, and serve as consultants to developers who wish to ensure that their buildings will be accessible. Some communities even provide financial assistance to businesses to upgrade their accessibility. Cambridge, Massachusetts, for example, established a Façade Improvement Program that provides businesses with matching grants of up to \$35,000 for façade improvements, which may include improved access for customers with disabilities, as well as the restoration of architectural details, better windows and doors, and well-proportioned signage and lighting. Over the past 10 years, dozens of Cambridge businesses have received matching grants and have been made accessible in the process.<sup>111</sup> Cambridge’s Commission for Persons with Disabilities provides guidance to business owners on ways to maximize accessibility for customers with disabilities and provides information on federal tax breaks available to small businesses that remove barriers to access.<sup>112</sup>

In communities large and small, 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, as the example of Nashville, Tennessee, demonstrates below. In addition to cost, in larger cities or towns, as the Kansas City, Missouri, example shows, the sheer volume of work to be done causes delays in making necessary changes, and complaints arise when they are not made quickly enough. In older communities where many historic structures need to be retrofitted to make them accessible, conflict sometimes arises between preservationists who worry about compromising the authenticity of the structures and disability

advocates whose primary objective is to increase access. According to Dennis Pratt, Architect and Accessibility Specialist at Alpha One in Maine and 1 of 12 members of the public appointed by the President to the Access Board,<sup>113</sup> lack of awareness is by far the biggest obstacle to progress. “The biggest barriers are attitudinal,” he says. “When people are sensitive to access issues for people with disabilities, they are more willing to do things to improve the environment.”<sup>114</sup>

In an effort to heighten awareness among people without disabilities about the barriers that people with disabilities face every day, disability advocates in some communities have implemented “sensitivity training” for the public and elected or appointed officials. In Bloomington, Indiana, for example, the Council for Community Accessibility (CCA) runs a program that gives people without disabilities the opportunity to spend the day navigating in a wheelchair or wearing dark glasses to simulate the experience of low vision. Program participants have included the mayor, deputy mayor, city department heads, and staff members of the Parks and Recreation Department, Public Works Department, and Street Department. During his training session using a wheelchair, Bloomington’s former Mayor John Fernandez got stuck in an inaccessible inner entrance door to City Hall; subsequently, an automatic door was installed.

Citizen complaints arising from experiences like Mayor Fernandez’s are often the impetus for change in the community. A better approach to increasing accessibility, however, would be ongoing investment in a built environment based on universal design principles that benefits everyone in the community. While we may be far from this larger, desirable goal, it is evident that community improvements made as a result of the passage of ADA are touching the lives of people without disabilities as well as those of people with disabilities. Standing on a busy city street corner, for example, one is more likely to see curb ramps being used by mothers pushing baby strollers and kids skateboarding than by people in wheelchairs. Doors that open automatically or with the touch of a button are just as useful to older people with limited strength and anyone carrying packages as they are to people with disabilities. Investment in and acceptance of alterations to the built environment may be an easier “sell” when their value to the community at large is apparent.

Despite the obstacles to making communities more “disability friendly,” such as those mentioned above, some cities and towns around the country have made this issue a priority and are addressing it in creative ways. Following is a sampling of some of these “best practices.”

**As a college town, Bloomington/Monroe County, Indiana, involves university students in efforts to raise awareness about accessibility issues and certifies businesses that comply with accessibility guidelines.**

Building on ADA accessibility guidelines, the CCA, which provides oversight to the Community and Family Resources Department of the City of Bloomington, created the AccessAbility Decal Program to evaluate and certify businesses and buildings for accessibility. The CCA developed a two-page screening tool that enables evaluators to rate how well businesses in Bloomington are addressing such things as parking, access routes, entrances, elevators, stairs, interior and exterior common areas, public restrooms and drinking fountains, outdoor dining facilities, and customer service and employment. CCA formed a partnership with Indiana University and designated interior design students as evaluators who go into the community to review businesses using the screening tool. Generally, CCA picks a category—such as restaurants or clothing stores—then assembles a list of local businesses in the chosen category and sends the students out to evaluate the businesses on the list. Sometimes, however, businesses request an evaluation.

Following each of the evaluations, a letter detailing necessary improvements is drafted by the Community and Family Resources Department, signed by the CCA chairperson, approved by the city’s legal department, and sent to the business owner, who voluntarily makes the recommended improvements. A representative from the Community and Family Resources Department or a volunteer from the CCA will reassess the business until all the improvements have been made. When improvements are successfully completed, an “AccessAbility Decal” is awarded to the business at a public ceremony. These colorful 4” x 6” decals (see Figure 4) can be displayed in a conspicuous place such as the front door or a window to notify the public of the business’s new status. The first decal was awarded in 1993, and about 80 decals have been awarded to date.

Future plans for this project are to form a partnership with Ivy Tech College and train architecture students to conduct the reviews as well. In addition, in mid-2004, the Chamber of Commerce's Diversity Committee will issue a 16-page booklet designed to inform businesses about ADA accessibility requirements. The booklet includes a copy of the survey and contact information for CCA so that businesses can request reviews, thus potentially expanding the reach of the decal program to hundreds of businesses.

For more information, see the City of Bloomington, Indiana, Web site at <http://bloomington.in.gov/egov/apps/services/index.pl?path=details&id=903&action=i&fDD=1-303>.



**Figure 4.** Sample of the AccessAbility Decal signifying that a business meets accessibility requirements of the Council for Community Accessibility (CCA) in Bloomington/Monroe County, Indiana.

**In Kansas City, Missouri, a dedicated curb ramp crew ensures that streets are made accessible for people with disabilities.**

When the Deputy Director of Public Works in Kansas City learned from Michele Ohmes, the city's ADA/Disability Specialist, of long delays in constructing and servicing curb ramps in the city, he called together staff members from the Engineering Division and the

Streets and Traffic Division to discuss what could be done about the problem. The director of the Streets and Traffic Division had an idea for solving it but, concerned about using resources wisely, he first asked Ohmes whether she believed that a dedicated curb ramp crew could be kept busy in Kansas City. Curb ramp targets in the city had not been met for the past three years and there was quite a backlog, so Ohmes quickly assured him that a crew could be kept very busy. Now, with a dedicated crew, citizen requests for curb ramps are usually met within one month, and sometimes in as little as one week. Citizens send requests for curb ramps directly to Ohmes or to the city's Action Center, a central point of contact for city services, which forwards them on to Ohmes. When there is a lull in requests from residents, Ohmes directs her crew to work in areas that she has identified. Since the program was initiated in 2000–01, approximately 400 curb ramps have been completed along thousands of miles of roadway.<sup>115</sup>

For more information, contact

Michele S. Ohmes

Email: Michele\_Ohmes@kcmo.org

For information, see Ohmes' book *ADA and Accessibility, Let's Get Practical*, published by the American Public Works Association, available at [www.apwa.net](http://www.apwa.net).

**The Nashville, Tennessee, Comprehensive Sidewalks Program is an ambitious plan that not only makes the city more accessible for people with disabilities but improves quality of life for all of Nashville's residents.**

As the Kansas City example demonstrates, it is often a big challenge for a large metropolitan area to alter and repair sidewalks to be ADA compliant. However, it requires a tremendous effort to ensure accessibility for people with disabilities when much of a city has no sidewalks at all. Such was the case in metropolitan Nashville, Tennessee, but building and improving the sidewalks of Nashville and Davidson County has been a primary goal for Mayor Bill Purcell, first elected in 1999, and then reelected in 2003.

In 2002, after a yearlong commissioned study during which the streets and every foot of Nashville's 727 miles of sidewalk were assessed and community members were surveyed, the Mayor's office unveiled the "Nashville-Davidson County Strategic Plan for Sidewalks and Bikeways."<sup>116</sup> The plan was prepared by outside contractors under the direction of a Citizen's Advisory Committee (CAC) that includes advocates for people with disabilities, a physical therapist, community health specialists, avid walkers, and cyclists. In the final plan, a detailed scoring system was devised to prioritize all sidewalk repair and construction projects. Priorities are chosen based on the necessity of the project for ADA compliance, the number of people affected, the types of people affected (e.g., children, seniors, and people with disabilities), and whether the projects provide access to key services identified in public opinion surveys, such as schools, libraries, parks, stores, senior centers, and assisted living facilities. The plan originally scheduled all projects for completion by 2015, assuming at least \$20 million per year could be allocated for this purpose, with 1.5 percent yearly increases to account for inflation and rising costs.

Public input has been incorporated at all stages of the planning process and continues to be highly valued. The Comprehensive Sidewalk Program's Web page (<http://pw.nashville.gov/WEBPROD/SidewalkMain.asp>) encourages public feedback and questions and includes an interactive map of Nashville that shows all sidewalks and the proposed schedule of both sidewalk repair and sidewalk construction projects.<sup>117</sup> A series of public meetings were held at the beginning of the project, and the plan calls for a new series of meetings to be held every two years to reevaluate the priority ranking system and alter it, if necessary. In addition, before the design process begins, a public meeting is held for each block scheduled to have new sidewalks built to reassess public support for the project.

It is particularly difficult and expensive to add standard sidewalks to streets with public rights-of-way<sup>118</sup> that cannot easily accommodate them. Streets are often too narrow, or obstructions such as trees, mailboxes, or drainage ditches may complicate the construction of sidewalks. In these cases, property owners might be asked to donate or sell additional right-of-way to the city (in Nashville, the city government has full jurisdiction over

existing rights-of-way, including all sidewalks), or creative design solutions need to be considered.

In some cases, arrangements are made to provide access for seniors and people with disabilities, even if the project does not score high in the priority ranking system. One example is Old Hickory Towers, a high-rise apartment complex for older people in an industrial neighborhood. The only way residents can access nearby neighborhood stores is to walk alongside heavily trafficked Robertson Road, which does not have a sidewalk. The plan to build sidewalks on Robertson Road was not given high priority through the strategic plan's ranking system, because the only people directly affected are the residents of the high-rise itself. However, according to Renee Jackson, Sidewalk Program Manager for the Department of Public Works, "It was dangerous for people to go up and down a busy street in electric-powered wheelchairs, and we didn't want people to risk life and limb."<sup>19</sup> City officials, working with the building management and residents, considered several options for decreasing the danger, including a proposal to arrange for the Metropolitan Transit Authority to provide seniors with rides to local stores. Ultimately, it was decided that the best and most cost-effective interim plan was to create a walkway on the grounds of the complex itself to connect existing pathways to a less busy side street with access to a grocery store and several other shops. The city subsequently acquired an easement from Old Hickory Tower's owners to build the path on their property. "The chosen plan provides more freedom for building residents than the plan to provide rides through the Metropolitan Transit Authority," says Jackson, "And the new path will also be a great place for residents to exercise."

Jackson explains that the biggest problem with completing proposed sidewalk construction is funding. Fifty-five million dollars has been spent on sidewalks since 1999, and Mayor Purcell was able to secure an additional \$20 million for sidewalk construction in the city's Capital Plan for FY 2003/04. However, because of a budget crunch, only \$5.75 million was allocated to the program for FY 2004/05. According to Jackson, this funding will be used to finish the process of making existing curb ramps compliant with ADA regulations. Jackson says that the hardest part of her work is not knowing how much



funding to count on each year, and explaining to community members why their needs cannot be addressed right away:

We explain to them how the ranking process works and tell them how to get involved, but there are budget constraints. Still, we know what the needs are because the strategic plan is in place. It's just a matter of checking things off the list.

**In Portland, Maine, providing access to historic buildings for people with disabilities is a challenge that has been successfully—and cleverly—met.**

Portland, Maine, is generally a disability friendly city where the local government—including the agencies that have jurisdiction over historic properties—the business community, and the public support accommodations for people with disabilities. For example, the city is quite lenient in granting variances to zoning ordinances so that businesses and private homes of people with disabilities can be made more accessible. As a busy port city, with a lot of ferry and international boat traffic, Portland has invested a good many resources in making its ferry terminals, dock facilities, and boats that serve the surrounding islands accessible to people with disabilities, providing ramps and ingenious lift systems to board people with wheelchairs and accessible bathrooms at the dock and on the ferries. As an old city with many historic structures, Portland has successfully adapted some of these buildings to make them accessible to people with disabilities, often using innovative technical solutions. A case in point is the Portland Observatory.

Built in 1807, the Portland Observatory is an octagonal 86-foot-high tower that served as the communication station for Portland's busy harbor. Using a powerful telescope at the top of the Observatory, Lemuel Moody (1768–1846), the sea captain and entrepreneur who had the tower built, was able to identify incoming ships up to 20 miles away. He then raised flags to signal local merchants, who would have time to hire crews and reserve berths before the ships docked. Lemuel also used his telescope to make 24-hour weather forecasts for the Portland area. The tower ceased its “signalizing” operations in 1923. By the early 1990s, engineers discovered that seeping moisture and powder post beetles had done so much damage to the structure that it seemed on the verge of collapse. Several

years later, the Portland Observatory Restoration Trust raised \$1.28 million for restoration of the tower, which started in 1998 and was completed in 2000. The Observatory is now a museum.

To conduct the restoration project, the Observatory was virtually dismantled and rebuilt. Access to the building entrance is not on the ground floor, but up a steep exterior staircase that visitors must climb to get to the entrance door on the first floor. From there, visitors must climb additional flights of stairs to get to the top of the observatory. There was no room to add an interior elevator to facilitate access to the entrance on the first floor or to take people to the very top, so an ingenious solution was devised: People with disabilities were provided access to the first floor of the structure, where, using alternative formats, they could experience what visitors who climb to the top of the Observatory actually see.

First, at one side of the building, \$100,000 was spent to install a lift that emerges out of the ground at the push of a button to take passengers to the first floor entrance. There, passengers disembark onto a deck that takes them to the same first floor entrance that all visitors use to get into the building. Once inside, visitors who are able to climb the stairs to the top can do so. Those who cannot climb nonetheless are able to see the 360-degree view from the top with the help of a real-time Web cam supplemented by graphics and photographs that are on exhibit on the first floor. In fact, anyone interested in seeing the view from the Observatory can access the Web cam by logging onto [www.portlandlandmarks.org](http://www.portlandlandmarks.org). A photograph on the same Web site shows the location of the exterior lift and deck at the side of the building. In 2001, the National Trust for Historic Preservation bestowed a well-deserved Preservation Award to the Portland Observatory project.

## **Chapter 5: Provide Work, Volunteer, and Education Opportunities**

Many people with disabilities are able to find jobs on their own, in the same manner as their counterparts without disabilities—for example, through personal contacts, employment fairs, and internships. Others seek assistance in preparing for and finding work through state vocational rehabilitation programs.<sup>120</sup> Social Security’s Ticket to Work (TTW) program offers people with disabilities a third option. TTW is a work incentive program designed for people with disabilities who receive SSI or Social Security Disability Insurance (SSDI) benefits, with the goal of financial self-sufficiency. In many cases, it is possible for beneficiaries to reduce their Social Security Administration (SSA) cash benefits to zero and maintain their Medicaid, Medicare, and HUD rental subsidies. Under the TTW program, employment services are provided by Employment Networks (ENs) that are under contract with the SSA to provide employment-related services to individuals with disabilities seeking to become self-sufficient.<sup>121</sup>

Like millions of other Americans with disabilities receiving SSA benefits, Marie<sup>122</sup> received her TTW in the mail. She investigated the ENs in her area and applied for services from Alpha One. Alpha One, based in South Portland, Bangor, and Presque Isle, Maine, is a Center for Independent Living as well as an EN. At Alpha One, Marie met with Zahira and Gary, Employment Coordinators/Benefit Specialists, to begin the process of developing an Individualized Work Plan (IWP)—“a consensus between the individual and the EN on the individual’s employment goals and the methods used to achieve them.”<sup>123</sup>

From the EN perspective, it was imperative that Marie understand fully the provisions of the TTW program and the effects of employment on her existing SSA and other benefits. They began by cataloguing all of Marie’s benefits to determine the effects of work on each of them. The result of this thorough assessment was a work plan or “guide to independence,” as Alpha One calls it. This document outlines the steps that Marie will take to reach her goals of employment and financial independence. Marie’s Employment Coordinators/Benefit Specialists stressed the importance of reporting all work activity to SSA and related state and federal agencies. Marie was given detailed information on how to do this as well as template forms to make the reporting less confusing. In addition to the steps related to securing employment,

Marie's completed IWP contained plans for repairing her credit history, funding for car repair so that she could travel to work, and the use of work incentives related to her HUD-subsidized housing voucher, Medicaid, and child care subsidies.

In terms of her work preparedness, Marie is a high school graduate with some part-time work experience in retail. She contacted Alpha One to explore the TTW option with a very clear goal in mind—to work in a retail business that offered management training so that one day she could become a store manager. On her own, Marie found a full-time job at a local retail store. She is now on a management-training track and her goal seems well within reach.

A fundamental principle of Title I of ADA is that people with disabilities who want to work and are qualified to work must have an equal opportunity to work.<sup>124</sup> The employment provisions under ADA apply to private employers, state and local governments, employment agencies, and labor unions.<sup>125</sup> Employment nondiscrimination requirements went into effect on July 26, 1992, for employers with 25 or more employees, and July 26, 1994, for employers with 15 or more employees. The requirements apply to all employment-related activities such as recruitment, advertising, job applications, hiring, firing, layoff, leave, advancement, compensation, fringe benefits, training, and tenure.<sup>126</sup> The Equal Employment Opportunity Commission (EEOC) enforces compliance with ADA's Title I employment provisions. In FY 2002, for example, the EEOC received 15,964 complaints of disability discrimination, resolved 18,804 charges, and recovered \$50 million in monetary benefits, not including monetary benefits obtained through litigation.<sup>127</sup>

A qualified individual with a disability who wants to work must meet the skill, experience, and education requirements of the job and be able to perform the duties with or without "reasonable accommodation." Reasonable accommodations are any changes to the work environment that allow people with disabilities to carry out job functions or have equal access to benefits available in the workplace.<sup>128</sup> Common accommodations include the following:

- Physical changes (e.g., installing a ramp; modifying a workspace or restroom)
- Sign language interpreters for people who are deaf

- Readers for people who are blind
- Quiet workspaces to reduce distractions for people with mental disabilities
- Training and written materials in accessible formats (e.g., Braille, audiotape, computer disk)
- TTYs for telephones
- Hardware and software to make computers accessible for people with vision impairments, or who have difficulty using their hands

Employers are required to make accommodations for qualified employees or job applicants as long as they do not impose an “undue hardship.” An undue hardship is “an action requiring significant difficulty or expense” in light of the nature and cost of the accommodation relative to the size, resources, and structure of the employer’s operation. Thus, larger businesses are expected to expend greater effort and expense in providing accommodations than smaller businesses.<sup>129</sup>

A 2003 “Work Trends Report” by the John J. Heldrich Center for Workforce Development at Rutgers University found that only one of four (26%) businesses employed at least one person with a disability.<sup>130</sup> According to the report, common reasons that employers don’t hire people with disabilities include the following: discomfort hiring people with disabilities; perceptions that people with disabilities cannot perform the kinds of jobs they have; beliefs that jobseekers with disabilities lack skill and experience; and lack of physical accessibility and fear of the cost of reasonable accommodation.<sup>131</sup> At the same time, the report provides data that addresses at least some of these reservations. For example, 73 percent of employers report that employees with disabilities did not require accommodations. Of those employers that did provide accommodations, 61 percent reported that the average cost of the accommodation was \$500 or less; 29 percent reported the cost was less than \$100. Moreover, the report cites a 30-year study conducted by the Dupont Corporation that found that 90 percent of workers with disabilities had above-average job performance, attendance, and safety records.<sup>132</sup>

Although there has been a small increase over the last decade in the percentage of adults with disabilities who are employed,<sup>133</sup> the unemployment rate among adults with disabilities is still

unacceptably high. The 2004 N.O.D./Harris Survey of Americans with Disabilities shows that working-age adults with disabilities are half as likely as working-age adults without disabilities to be employed (35% versus 78%),<sup>134</sup> and people with severe disabilities are less likely to be employed than those with slight disabilities (21% versus 54%).<sup>135</sup> Sixty-three percent of unemployed adults with disabilities say they would like to work,<sup>136</sup> but obstacles to finding appropriate employment abound. According to the 1994–95 National Health Interview Survey,<sup>137</sup> the most common obstacles include the following: no appropriate jobs available, lack of transportation, lack of appropriate information about jobs, inadequate training, and fear of losing health insurance or Medicaid.

The Federal Government has instituted tax incentives for employers and has established several initiatives and programs to help increase employment opportunities for people with disabilities:

## **Tax Incentives**

Tax credits are available for small and larger businesses that remove architectural barriers, and for businesses that employ people with disabilities referred from rehabilitation agencies:<sup>138</sup>

- The Disabled Access Tax Credit provides “eligible small businesses”<sup>139</sup> with a 50 percent tax credit for “eligible access expenditures” above \$250 that do not exceed \$10,250 for a taxable year. Examples include removal of architectural, communication, physical, or transportation barriers; making written materials accessible to people with visual impairments; making oral materials available to people with hearing impairments; or acquiring or modifying equipment or devices for people with disabilities.
- With the Tax Deduction to Remove Architectural and Transportation Barriers to People with Disabilities and Elderly Individuals, the Internal Revenue Service allows a deduction up to \$15,000 per year for expenses used to make a facility or public transportation vehicle owned or leased by a business accessible and usable by people with disabilities.
- The Targeted Jobs Tax Credit allows employers to receive a tax credit up to 40 percent of the first \$6,000 of first-year wages of a new employee with a disability referred by state or local vocational rehabilitation agencies, State Commission on the Blind, or the U.S. Department of Veteran Affairs, and certified by a state employment service. An employee

must complete 90 days or 120 hours of employment for his or her employer to qualify for the credit.

## **New Freedom Initiative**

One of the goals of the NFI is to integrate Americans with disabilities into the workforce.<sup>140</sup>

Some key accomplishments include the following:

- Establishing the Access to Telework Fund to allow individuals with disabilities to work from home or other sites and have increased access to computers and other equipment, including adaptive equipment. The Department of Education's Rehabilitation Services Administration has funded 20 projects under this program.
- Promoting best practices through a partnership between the EEOC and several states (including Maryland, Vermont, Washington, Florida, Utah, and Kansas, as well as more states are scheduled for participation in this program) to promote hiring of people with disabilities in state government jobs.<sup>141</sup> Under this partnership, the EEOC reviews hiring, retention, advancement, and reasonable accommodation practices; provides consultation, outreach, and technical assistance; and will issue a report highlighting best practices that can serve as a model for other states.<sup>142</sup>
- Increasing the SSA's budget to fund several demonstration projects aimed at removing disincentives and providing appropriate employment supports for individuals who want to work.

In addition, the NFI is promoting the implementation of the TTW program, full enforcement of ADA, and understanding and using tax incentives; enhancing the Workforce Investment System; and promoting the Federal Government as a model employer. For more information, see the NFI Progress Report at <http://www.whitehouse.gov/infocus/newfreedom/newfreedom-report-2004.pdf>

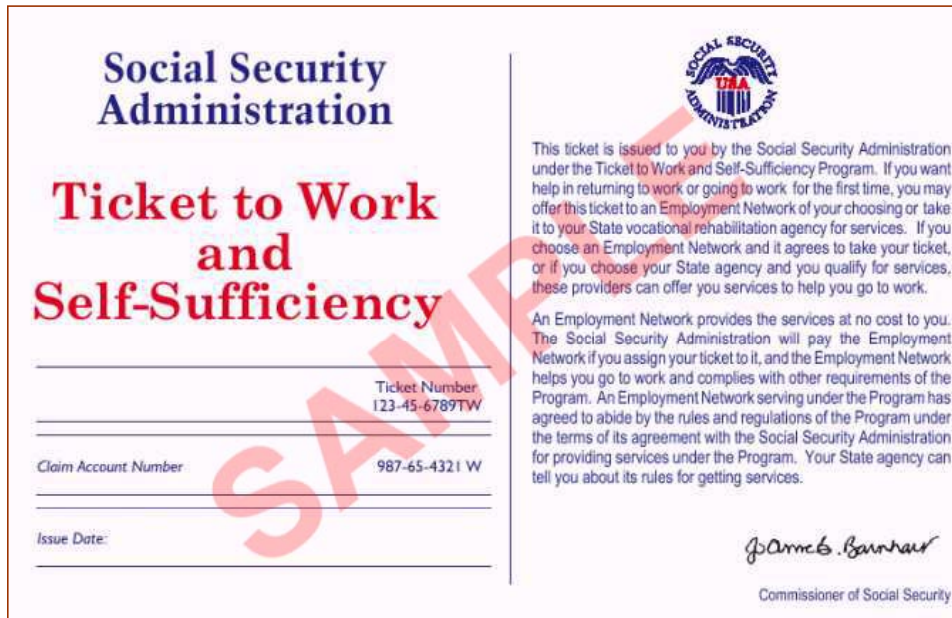
## **The TTW and Self-Sufficiency Program**

The TTW and Self-Sufficiency Program, part of the TTW and Work Incentives Improvement Act of 1999, is a voluntary, nationwide program whose goal is to increase opportunities for SSA

disability beneficiaries aged 18 to 65 to obtain employment, vocational rehabilitation, and support services, and ultimately to replace their SSA benefits with earnings from work.<sup>143</sup> This legislation also addresses SSA beneficiaries' concerns about losing their health insurance during employment by extending Medicaid and Medicare coverage, gives exemptions from continuing disability reviews, and provides free education and employment services to beneficiaries.

More than 10 million people are eligible to participate in this nationwide program. As of mid-August, 2004, more than 9.5 million tickets were issued and 59,523 people were using their TTW vouchers at 1,149 participating ENs or 79 state vocational rehabilitation agencies.<sup>144</sup> ENs are private organizations or government agencies that have agreed to work with the SSA to provide employment services to beneficiaries with disabilities.<sup>145</sup> These ENs include One-Stop Centers and Workforce Investment Boards, disability and rehabilitation service providers, employment agencies, state and local government agencies, hospitals, foundations, and others. The services offered vary and may include listings of education programs, job search assistance, job training, job placement, and a variety of other offerings, depending on the capacity of the EN provider. Beneficiaries may contact one or more ENs to locate suitable programs.<sup>146</sup> After the beneficiary and the EN agree to work together, they develop a customized employment plan based on the beneficiary's goals and desired earnings. ENs receive revenue from the SSA for their services (see Figure 5).





**Figure 5.** Sample ticket used in the TTW and Self-Sufficiency Program.

## **Job Accommodation Network**

The Job Accommodation Network (JAN) is a free consulting service of the Office of Disability Employment Policy (ODEP) of the U.S. Department of Labor. JAN's mission is to facilitate employment and retention of workers with disabilities by providing information on job accommodations and technical assistance to businesses and people with disabilities who are self-employed. Person-to-person technical assistance services include toll-free consultation regarding individual worksite accommodation, individual self-employment accommodation, and individual consultation and referral regarding ADA and other disability legislation. JAN's annual symposium and outreach activities provide additional training to private and public organizations. Electronic technical services include JAN's accessible Web site (<http://www.jan.wvu.edu/>), which includes more than 300 disability-specific accommodation publications; JAN's Small-Business and Self-Employment Web site (<http://www.jan.wvu.edu/sbses/>), which contains information about self-employment and small-business ownership opportunities for people with disabilities; and JAN's Searchable Online Accommodation Resource (<http://www.janwvu.edu/soar>), which provides personalized accommodation information. Additional resources include JAN's quarterly newsletter and topical news flash, *Consultants' Corner*.

## **Computer/Electronic Accommodations Program**

The Computer/Electronic Accommodations Program (CAP) was established in 1990 by the Department of Defense (DoD). In October 2000 CAP became the Federal Government's centrally funded accommodations program through the National Defense Authorization Act. CAP's mission is to provide AT and accommodations at no cost to requesting government agencies to ensure that people with disabilities have equal access to the information environment and opportunities in DoD and throughout the Federal Government.

- The Employment Program<sup>147</sup> assists human resource managers and hiring officials with hiring, recruitment, promotion, and retention of people with disabilities.
- Program Accessibility<sup>148</sup> involves technical assistance, training, and accommodations to meet communication accessibility requirements.
- System Accessibility<sup>149</sup> refers to increasing access to AT, and the accessibility of electronic and information technology.

Following are examples of several community-based efforts—some large, others considerably smaller but no less notable—to increase employment opportunities for people with disabilities. Within these efforts, people with disabilities may find training and internship/volunteer opportunities as well.

### **In Chicago, Illinois, the mayor is committed to increasing the employment rate for people with disabilities and has implemented a number of measures to help reach that goal.**

From Mayor Richard J. Daley's time to the current Mayor Richard M. Daley, disability issues have been on the forefront in Chicago.<sup>150</sup> This mayor's Employment Fair for People with Disabilities is an annual event that began in 2001; the Mayor's Office for People with Disabilities (MOPD) has hosted Chicago's version of National Disability Mentoring Day (NDMD) since 2001; and, in October 2002, Mayor Richard M. Daley created a Mayoral Task Force on Employment of People with Disabilities through an Executive Order. In a time of fiscal crisis, nearly a quarter of a million dollars annually has been allocated to the task force. To manage task-force activities, Gil Selders was named Deputy Commissioner to the MOPD.

The task force is cochaired by David Hanson, commissioner of the MOPD; Jackie Edens, commissioner of the Mayor's Office of Workforce Development; and William Osborn, chairman and CEO of the Northern Trust Corporation. The task force has more than 100 members and consists of 5 workgroups, each with a leader and an associate leader. Each workgroup has several members from the business, government, economic development, civic, academic, and disability communities. The workgroups are required to submit reports with findings and recommendations to Mayor Daley each year, in May 2003, May 2004, and July 2005. The task force is slated to end on July 26, 2005, the 15th anniversary of signing ADA into law.

The task force's vision focuses on increasing the employment rate among people with disabilities so that it comes as close as possible to the employment rate of the general adult population. A description of the workgroups and their accomplishments follows.

- **Supply Side Development and Coordination Workgroup.** This workgroup created a new entity called the Provider Leadership Network (PLN). The PLN is composed of disability service providers, such as the Rehabilitation Institute of Chicago, the Chicago Lighthouse for People Who are Blind or Visually Impaired, and the Illinois Office of Rehabilitation Services, who supply a talented and qualified pool of job applicants with disabilities to meet the needs of Chicago's businesses. Overall, from January through June 2004, the PLN assisted nearly 350 Chicago residents with disabilities in obtaining employment through three mechanisms:
  - Partners for Inclusive Environment was created in 2001 and coordinates event-driven, targeted job match fairs for people with disabilities, prescreens job applicants and employers, and educates employers about ADA provisions.
  - AbilityLinks.org, launched in July 2001, is a Web site that connects people with disabilities to employers. Employers complete an online form that describes the available jobs and the prerequisite skills, education, and training; job applicants fill out an online questionnaire detailing their skills and capabilities; and Web site staff use the information to match job candidates with employers. The Web site has a search function that enables jobseekers to look for jobs and employers to look for job candidates.

- Employ Alliance is funded by a grant from the Illinois Council on Developmental Disabilities. Employ Alliance locates qualified employees with disabilities through the 280 partners in the PLN and matches them with interested employers. Through this program, 48 people with disabilities have been placed from the time of the Alliance's first monthly meeting in December 2003 to July 2004.
- **Procurement and Entrepreneurial Opportunities Workgroup.** This workgroup's mission is to increase the number of businesses owned or operated by people with disabilities that are certified to participate in the procurement programs offered by city agencies and the private sector. To achieve this goal, the workgroup implemented the Business Enterprises Owned by People with Disabilities certification program. Nine companies have been certified and 100 applications have been requested since they became available in November 2003. The listing of certified businesses will be circulated among city agencies such as park, education, and transportation departments as well as with representatives from the private sector.
- **Partnership for Economic Opportunities Workgroup.** In collaboration with the Chicago Chamber of Commerce, this workgroup developed the Chicago Businessland Leadership Network (CBLN), which shares effective business practices to increase employment opportunities for people with disabilities. The CBLN began with 8 member companies in the fall of 2003 and expanded to more than 50 companies from the private, public, and nonprofit sectors by July 2004. The CBLN developed a toolkit for businesses containing a wealth of information about understanding ADA, resources, reasonable accommodations, and hiring people with disabilities (available at <http://www.cbln.com>). The workgroup is working with state, county, and city officials to identify economic incentives for hiring people with disabilities, and will compile the information in a directory.
- **Opportunities for Youth Workgroup.** This group's mission is to make recommendations to improve employment outcomes for students with disabilities by addressing education, transition to employment, vocational rehabilitation, and adult service options to youth and young adults. The group will establish standards, goals, expectations, and staff development activities for transitioning youth with disabilities from

school to work. The workgroup was successful in having two young adults with disabilities appointed to the Youth Council of the Chicago Workforce Board. A major achievement for the workgroup was the workgroup leader's (Teresa Garate) promotion to the position of Director of Program Development, Innovation and Transition in the Chicago Public Schools (CPS). Garate will coordinate with all major office of the CPS and support increased access to general education initiatives, employment opportunities within CPS, and school-community programs.

- **Chicago as a Model City Workgroup.** This group worked with the City Law and Personnel Departments to revise the 1995 Reasonable Accommodation in Employment and Hiring Practices Policy. In addition, a centralized Reasonable Accommodation Account was established to help city departments defray the costs of making reasonable accommodations and to provide them with technical assistance. A Reasonable Accommodation Review Board will have the authority to evaluate and reverse initial decisions denying reasonable accommodation requests. And a system to track the nature and costs of reasonable accommodations, approvals, and denials is under development. Additionally, Mayor Daley authorized mandatory one-day training on reasonable accommodations for all 37,000 city employees. The training, entitled "The Intersection of Diversity and Disability," is expected to begin during the fall of 2004.

Chicago's commitment to increasing employment opportunities for people with disabilities is also reflected in two annual events: (1) Mayor Daley's Employment Fair for People with Disabilities, and (2) Chicago's participation in NDMD.

The most recent fair was held in July 2004 at Chicago's Navy Pier,<sup>151</sup> and drew approximately 2,000 jobseekers and 50 employers. Three hundred high school students attended to increase their awareness and begin their career development. Before the fair, participating company names were listed on the city's Web site so that jobseekers could "do their homework" and learn about the employers in advance. Some examples of the large companies in attendance were Sears, Roebuck and Company, U.S. Cellular, Walgreens, McDonald's Corporation, Northern Trust Bank, and the City Department of Personnel. Disability service providers such as the MOPD, Access Living, the PLN, and the Chicago Lighthouse were looking to hire people with

disabilities. A variety of workshops were offered at the fair, such as training in Internet job searches, effective resume writing, and benefits planning.

Chicago's participation in NDMD<sup>152</sup> in 2003 matched 135 16- to 24-year-old students with disabilities with more than 100 mentors from 60 employers in the business, government, and nonprofit sectors, many of whom were involved in the employment fair.<sup>153</sup> According to Commissioner Hanson, such events "assist in transitional career planning for students with disabilities and can significantly increase their likelihood of being employed."<sup>154</sup>

In addition to the accomplishments described above, many more activities are under way. The task force is preparing to launch a public education campaign to inform employers about the value of employing people with disabilities and educate employers and people with disabilities about resources to facilitate employment. In early fall 2004, the task force launched a user-friendly Web site, [www.disabilityworks.org](http://www.disabilityworks.org), that will post task force news and a calendar of events. And efforts are under way to train the staff at the city's 311 information line to respond to inquiries about the task force and disability issues.

For more information, contact

Gil Selders

Email: [gselders@cityofchicago.org](mailto:gselders@cityofchicago.org)

For more information about Chicago's NDMD, see the City of Chicago Web site at <http://www.cityofchicago.org>.

**Two of Maryland's employment programs for people with disabilities are employer driven and rely on partnerships to increase employment opportunities.**

The U.S. Business Leadership Network (USBLN), founded in 1994, is a national, employer-led effort by the U.S. Department of Labor's ODEP and supported by the U.S. Chamber of Commerce.<sup>155</sup> A local chapter, the Eastern Shore Business Leadership Network (ESBLN), won the 2003 USBLN Chapter of the Year Award for best practices in promoting employment of people with disabilities. In its citation, the USBLN said of the Maryland chapter:

The Eastern Shore Business Leadership Network (ESBLN) of the Salisbury Area Chamber of Commerce located in the Eastern Shore of Maryland is a proven leader in promoting the employment of persons with disabilities. As the first local chamber of commerce to directly sponsor a Business Leadership Network (BLN), the Salisbury Area Chamber [of Commerce] supports and demonstrates the BLN mission: that increasing employment opportunities for people with disabilities is good for business and good for people with disabilities. However, the ESBLN goes above and beyond simply helping its business members meet their labor needs. The organization has recognized the intrinsic value of people with disabilities as employees, consumers, and contributors to the social fabric of our society.<sup>156</sup>

Sponsorship by a chamber of commerce is important because it legitimizes the network and changes its status from a nonprofit, state-agency-type entity to a business strategy.

Today, the ESBLN has expanded to the entire Delmarva Peninsula—including Delaware, nine Maryland counties, and two Virginia counties—and recruited three additional county chambers of commerce (Talbot County Chamber, Cecil County Chamber, and Greater Seaford Chamber). With this expansion, the ESBLN can be promoted throughout its network of 4,000 businesses, individuals, and organizations, significantly increasing the pool of potential employers of people with disabilities.

Specifically, ESBLN's goals are to achieve the following:

- Provide employers with access to prescreened job candidates.
- Decrease the number of people with disabilities who are unemployed or underemployed.
- Provide employers with information about best practices, disabilities, support services, and tax incentives to facilitate employment, training, and retention of people with disabilities.
- Increase general awareness of people with disabilities as valuable employees, entrepreneurs, and consumers in communities.

Two strategies that ESBLN employs for meeting its goals are (1) a comprehensive Web site that provides resources to employers and job candidates and (2) partnerships with agencies in the public rehabilitation system, which play a key role in recruiting, hiring, training, and retaining workers with disabilities.

The ESBLN Web site ([www.esbln.org](http://www.esbln.org)) is the first site in the nation designed to link job-ready candidates with disabilities to employers across the Delmarva Peninsula. The Web site allows employers to search for prescreened job candidates and allows candidates and agencies to search for job openings with employers in specific geographic regions across the Delmarva Peninsula. The Web site, which is sponsored by various corporate members,<sup>157</sup> has been used as a model for BLNs in other locations around the country.

The ESBLN actively works with the Maryland CareerNet One-Stop,<sup>158</sup> which encompasses the Maryland Division of Rehabilitative Services (DORS). According to the USBLN Chapter of the Year Award bestowed on ESBLN, the effectiveness of the partnership between ESBLN and the colocated career center and department of rehabilitation services is demonstrated by an increase in “competitive employment outcomes” (i.e., the number of people with disabilities hired). For example, in 1998, DORS reported 182 successful competitive employment outcomes. In 2002, after working in partnership with the ESBLN and the one-stop career center for a couple of years, the number of successful outcomes had risen to 247, and, after a one-year follow-up, the retention rate of those employees was 85 percent.<sup>159</sup>

The governor’s QUEST<sup>160</sup> Internship Program for Persons with Disabilities is a successful program that helps people with disabilities gain work experience and become employable in Maryland.<sup>161</sup> The program is administered by the Disability Employment Workgroup, which is a partnership between the Office of Personnel Services and Benefits (OPSB, part of the Department of Budget and Management) and the Department of Disabilities. The Workgroup also includes representatives from other state agencies and the DORS.

The QUEST program started in 2000 with a budget of \$50,000 from the OPSB, which supported six-month contractual positions for approximately 10 interns. But the following year, Maryland’s hiring freeze resulted in changing the program’s structure to a volunteer program with a stipend.



Actually, this change was fortuitous. The program is now more flexible and open to a larger pool of candidates, because the requirements for volunteers are designed to be competency-based rather than to emphasize a required amount of relevant work experience to qualify for a position. Internship assignments are varied and have included jobs such as junior accountant, Medicaid program assistant, activity therapist assistant, communication and marketing trainee, and health records clerk. In 2004, 25 positions were filled. Interns receive a \$3,000 stipend for three months of full-time work and \$1,500 for part-time work, paid through the OPSB.

Typically, Maryland's OPSB promotes QUEST to state agencies with promotional materials, phone calls, and emails, and solicits agencies to participate in the program in the fall and winter. A booklet detailing available internships is sent out in January or February to DORS counselors in Maryland, who then find and refer job-ready candidates. Applications are distributed to candidates in March, and a kickoff event for agencies and internship supervisors is held in April. Applications are provided to state agencies during the QUEST Kickoff orientation event, which provides agency supervisors with information related to intern selection procedures, reasonable accommodation, available DORS resources, and related administrative activities. Then supervisors conduct interviews and make their selections. A memo of understanding is signed by the internship supervisor from the participating state agency, the intern, the DORS employment representative, and the Recruitment and Examination Division director in OPSB. Interns usually begin working by May. A graduation ceremony with interns and their supervisors was held on October 4, 2004, to celebrate the interns' accomplishments. In 2004, QUEST graduates will also be awarded a governor's citation for completing their recent internships.

The QUEST Internship Program benefits interns and agencies alike. Interns with disabilities gain valuable work experience, which helps them become more employable when and if they search for permanent employment, and agencies gain experience in hiring and working with people with disabilities. Steve Serra describes the program as a significant and moving experience for both interns and their supervisors.<sup>162</sup>

For more information about the ESBLN, see the ESBLN Web site at <http://www.esbln.org> or <http://www.usbln.org>.

For more information about the QUEST internship program, contact

Steven Serra

Email: [sserra@dbm.state.md.us](mailto:sserra@dbm.state.md.us)

**In Flint, Michigan, Career Alliance, Inc., a One-Stop Career Center<sup>163</sup> serving Genesee and Shiawassee Counties, is pilot-testing “Customized Works!,” a promising new program that may be instrumental in changing the way that One-Stop Centers, rehabilitation organizations, and other providers do business in terms of training and finding employment for people with disabilities.**

Michigan Works Career Alliance, Inc., is one of 25 agencies in Michigan that provides employment services to all working-age individuals in the state who need them. While states have a great deal of autonomy in how their One-Stop Career Centers are organized and what services they provide, they are mandated to accommodate all jobseekers, including people with disabilities. Few, if any, however, have gone as far beyond minimum federal guidelines for accessibility and inclusion as Career Alliance, Inc. For example, Career Alliance employs people with disabilities—in fact, about 30 percent of its workforce are people with disabilities. In addition, Career Alliance is pilot-testing a program that approaches expanding employment opportunities for people with disabilities in a new way.

Career Alliance is one of five grantees to receive funds from the U.S. Department of Labor’s ODEP to create a “customized employment” program. According to the ODEP, customized employment—

...is a process for individualizing the employment relationship between a jobseeker or employee and an employer in ways that meet the needs of both. It is based on a match between the unique strengths, needs, and interests of the job candidate with a disability, and the identified business needs of the employer or the self-employment business chosen by the candidate. This is a business deal.<sup>164</sup>

Customized employment starts with the development of an employment plan based on the strengths, needs, and interests of the job candidate with a disability. This is accomplished through an individualized assessment that involves listening to the person with a disability describe his or her experiences, interests, and abilities. Once the candidate's goals are established, potential employers are identified by looking for a match between the job candidate's expressed interests and skills and the nature of an employer's business. A preliminary job proposal is developed and presented to a potential employer, who has voluntarily agreed to negotiate an individualized position that meets the employment needs of the applicant and real business needs of the employer. A personal agent or "job developer" conducts the assessment, develops a plan for the job candidate, assists the candidate throughout the process, and provides follow-up services when appropriate. The idea here is not to try to fit the jobseeker into a preexisting employment slot, but rather to carve out a job from a traditional job description or negotiate a new position description that matches the applicant's aspirations with the unmet needs of the employer.<sup>165</sup>

For example, an individual's assessment showed that he has skills to do filing. He also expressed a strong desire to be a police officer. To meet both the individual's skills and desires and the employer's needs, a carved job was negotiated with a county sheriff's department that incorporates tasks of organizing and filing misdemeanor arrest reports and traffic citations.

The Career Alliance (CA) program in Flint, Michigan—an area with one of the highest unemployment rates in the country—is called "Customized Works!" and has been in operation for just one year. During this first year, staff for the grant were selected and trained, a strategic plan was developed and committees formed, and 10 initial eligible<sup>166</sup> "customers" (i.e., jobseekers) and more than 40 community partners and provider agencies were selected to participate in the program. CA staff estimate that it may take from 18 to 24 months to match a jobseeker with an employer. CA's goal is to work with 60 customers over the five-year period of the grant.

Although the program started recently and does not have many results to share as yet, it is a program worth watching over the next four years. If it is successful, Customized Works! as well as the other grantee customized employment programs may become a model for One-Stop

Centers everywhere to use with all of their customers. If the system works for the most difficult-to-serve population—people with disabilities—then it should work for others as well.

For more information about customized employment, see the Department of Labor’s Web site at [www.dol.gov/odep/tech/employ.html](http://www.dol.gov/odep/tech/employ.html). For more information about Customized Works! see [www.careeralliance.org/cworks/](http://www.careeralliance.org/cworks/).

**Uptown Bill’s Small Mall in Iowa City, Iowa, houses a group of small businesses owned and operated by people with disabilities.**

In 2001, with support from the Extend the Dream Foundation, Thomas Walz,<sup>167</sup> former Dean of the School of Social Work at the University of Iowa, founded Uptown Bill’s Small Mall—a group of small businesses in downtown Iowa City that are owned and operated by low-income people with disabilities who had never worked before. The businesses include—

- Uptown Bill’s Coffeeshop
- Bill’s Bookmart
- Leslie’s Luxuries (antiques and collectibles)
- Mr. Ed’s SuperGraphics
- Mad Hatter Room (a venue for local music that is alcohol and smoke free, and is also used as a center for Alcoholics Anonymous meetings)
- Gretchen’s Vintage Apparel

Two related offsite businesses are—

- Mick’s Workshop (furniture refinishing and improvement)
- Funk’s Grove Lawn and Garden

The business owners include people with chronic mental illness, cerebral palsy, brain injury, post-traumatic stress disorder, diabetes, and dual diagnosis of mental illness and alcoholism; some use wheelchairs. In addition to the eight owners, Uptown Bill’s Small Mall has dozens of

volunteers who maintain property. Many of the volunteers are people with disabilities; others are social work students from the University of Iowa.

In 2002, Walz received the Best Accessible Design Award for the mall from the Governor's Commission of Persons with Disabilities. The mall, open 365 days a year, is located downtown and can be easily accessed by people living nearby. With its homey quality, the mall has become a neighborhood center that hosts community events and holiday meals.

Using Community Development Block Grants, Iowa City provided a 100 percent rent subsidy to the mall for its first three years and will provide a 50 percent subsidy for another three years. The mall is associated with the University of Iowa School of Social Work, School of Business, School of Nursing, Disabilities Studies Program, and the Department of Psychology.

The idea for Uptown Bill's Small Mall was inspired by Bill Sackter, a man with mental retardation who had been committed involuntarily to a state hospital and was discharged during the 1960s deinstitutionalization movement. Tom Walz gave Bill his first job—making coffee at the School of Social Work. In time, an empty classroom was transformed into a coffeeshop and Bill's work evolved into "Wild Bill's Coffeeshop." Bill operated the shop from 1974 until 1983, when he died at the age of 70. His life has been immortalized through a number of popular films and books.<sup>168</sup>

After Bill's death, Wild Bill's Coffeeshop remained part of the University of Iowa School of Social Work. Now, Uptown Bill's Small Mall has a contract with the University of Iowa to continue to run Wild Bill's Coffeeshop, with all of the income over employee salaries going to the university. The coffeeshop is operated by people with severe disabilities, each of whom works about four hours a week. In 2002, Tom Gilsean, the coffeeshop manager and a doctoral student in social work at the University of Iowa, received the Small Employer of the Year Award from the Iowa Commission of Persons with Disabilities in recognition of the number of people with disabilities hired since 1973.

The businesses in Uptown Bill's Small Mall are supported by a combination of grants, public funding, volunteers, and their own profits. They provide paid and volunteer opportunities for

people with and without disabilities. They also provide an important service to the surrounding community as well as an educational opportunity for university students to work with people with disabilities. The ultimate goal is for the businesses to be self-sufficient and mainstreamed into the larger business community.

For more information, see Uptown Bill's Web site at <http://www.uptownbills.org>.

## Chapter 6: Ensure Access to Key Health and Support Services

In 2001, three people in Los Angeles who use wheelchairs consented to mount camcorders on their chairs and film themselves as they went through and commented on their daily activities and thoughts over an 18-month period. From this footage, physician-filmmaker Gretchen Berland<sup>169</sup> created *Rolling*, a 70-minute documentary that chronicles the ups and downs of their lives. One of the three subjects, Vicki Elman, is a middle-aged woman who has had multiple sclerosis for 20 years, lives alone, and has been using a motorized wheelchair for the past six years to get around. Part of the film follows Elman through a particularly challenging—and, unfortunately, not unusual—episode in which her chair malfunctions and she struggles to get it fixed.

We first see Elman in a series of increasingly frustrating phone calls with her insurance company in which she explains that the chair has not been working properly for four months and tries to secure authorization to get it fixed. Then the wheelchair seriously malfunctions over Memorial Day weekend. Elman tries to contact the repair company, but she can't reach anyone because of the holiday. The controls that allow her to lift her legs off the floor are broken, so her feet and ankles drag on the ground, and she has multiple cuts and bruises on her legs as a result. On the Tuesday after the holiday, Elman goes to her doctor's office to take care of her injured legs and see what her doctor can do to expedite repair of the wheelchair. Without her wheelchair, explains Elman, she cannot get in and out of bed or use the bathroom at home.

The doctor examines Elman's legs and looks worried. He tells her that his office cannot fix the wheelchair. The best he can do, he says, is to "call the repair company and harass them" so that they attend to Elman's wheelchair problems right away. But, he adds, even this will take a while to accomplish and he is concerned that, in the meantime, Elman's legs will get worse. Ideally, Elman explains, she would find a replacement chair to use while hers is being repaired, but the company does not rent the kind of chair she needs. The doctor tells Elman that he thinks she would be safer if she had full-time care, so he has arranged for her to stay in a "convalescent home" during the time the chair is under repair.

We next see Elman struggling to enter the convalescent home—the front door is not wheelchair accessible. At first there doesn't seem to be anyone at the front desk to respond to her calls for help, but soon an attendant spots her and helps her in. Despite her disability, Elman is quite independent at home. In the convalescent home, however, she is almost totally dependent, and it's clear that she is not used to being in that position. At one point, she asks an attendant to help her get out of bed to go to the bathroom, but the attendant refuses and tells her to use the bedpan instead. This is the last scene Elman is allowed to film in the convalescent home. She stays there for a full four weeks before her repaired chair is returned to her.

Viewers of the film learn that despite the challenges Elman faces on a daily basis, she is an active disability advocate. After weeks of planning, she travels to San Diego for a meeting of Californians for Disability Rights. Elman has been elected president of her local chapter and is working on legislation that she hopes will make it easier for people with disabilities—including the 1.6 million people in the United States who use wheelchairs—to live at home “rather than end up in a convalescent home” as she did. The pending legislation is called the Vicki Elman Community Living Act.

For many people with disabilities, durable medical equipment (DME) or AT is essential to maintain their health, functional ability, and independence. However, most health plans, especially public programs that people with disabilities rely on for health insurance and other types of assistance, have complex policies and guidelines for the kinds of equipment or technology they cover.<sup>170</sup> People with disabilities are affected by restrictive definitions of “medical necessity” and the decision making processes of managed care organizations.<sup>171</sup> A study of medical decisions made by managed care organizations in California, for example, found that requests for DME are among the most likely to be denied on the basis of medical necessity.<sup>172</sup> Along with these restrictive health plan decisions, financial barriers are the most common reason why people with disabilities may not have the assistive equipment they need.<sup>173</sup> Findings from a 2003 national survey reveal that, among those who use such equipment, one of five said that they have serious difficulties paying for it.<sup>174</sup>

Obtaining, replacing, or repairing DME and AT is often a complicated task, even for people skilled in navigating health plan coverage issues.<sup>175</sup> Old wheelchairs can be expected to break



down with increasing frequency; they have a life expectancy of five to seven years before they must be replaced. As Vicki Elman's story illustrates, once a chair does break down, it may take a month or more to repair it or obtain a new, custom-fitted one. Users often are unable to convince health plans that a new one might be needed before the current one becomes inoperable. In the meantime, the use of a poorly functioning or inadequate wheelchair can lead to a decline in physical health and more frequent use of costly health care services.<sup>176</sup>

Access to appropriate, functioning DME and AT is far from the only barrier that people with disabilities face when it comes to interacting with our fragmented health care system. Results of a national survey by the Henry J. Kaiser Family Foundation<sup>177</sup> reveal that despite their well above average use of health care services, individuals with disabilities face greater barriers to access than does the rest of the population. Providers of health services are often ill-equipped to meet the needs of people with disabilities. While the majority of survey respondents say they have a regular doctor, one of four report having had trouble finding a doctor who understands their disability. Although the vast majority of people with disabilities are covered by some type of health insurance, more than one of six (17%) report difficulties finding a doctor who accepts their insurance, and the rates are even higher (nearly 25%) among those covered by Medicaid, with or without Medicare as a supplement. Paying for prescription drugs and dental care was cited in the survey as a serious problem by nearly one-third of the respondents.

Studies find that, despite their frequent encounters with the health care system, people with disabilities are less likely than the general population to receive the range of preventive services they need, or they receive these services less frequently than recommended.<sup>178</sup> Preventive care is often overlooked, yet people with disabilities are susceptible to chronic conditions to the same or greater degree than the general population and are at risk for secondary conditions that result from their primary impairment—for example, women with mobility impairments experience an elevated risk for secondary osteoporosis at earlier ages.<sup>179</sup> To better assess the magnitude of these and other health disparities between people with disabilities and people without disabilities, Healthy People 2010<sup>180</sup> is including health goals for people with disabilities as a subgroup similar to other populations requiring special attention.<sup>181</sup>

People with disabilities, like all people, prefer to live at home and receive whatever health care and support services they need in the community. The complexity of issues related to the various health service needs of this group creates enormous challenges for states and local communities, consumers, advocacy groups, and policymakers. Serving people with disabilities in a community setting often requires changes in the financing and structure of health care delivery systems, such as more funding for community health centers, improved transportation services for people with mobility limitations, housing programs that are integrated with long-term support services, and the inclusion of people with disabilities and their advocates in service planning and delivery.<sup>182</sup>

Across the country, states have achieved varying degrees of progress in helping individuals with disabilities live independently in their communities by providing access to affordable, quality health care and long-term support services. Several states, for example, are exploring how to provide more cost-effective care for people with disabilities. Increasing demand for Medicaid and/or Medicare services has led them to pursue the option of enrollment in managed care. These states believe that some form of high-quality managed care is the best way to broaden access, contain costs, and increase quality of care for this population. A key component of many of these programs is “care coordination,” which goes beyond the medical model of disease management. Successful programs ensure that the diverse medical and psychosocial needs of beneficiaries with disabilities are identified and met, focus on wellness and prevention, and manage both covered as well as noncovered services.<sup>183</sup> Two such models, Minnesota Disability Health Options (MnDHO) and Wisconsin Partnership Program, are profiled in this chapter.

To meet the objectives of the *Olmstead*<sup>184</sup> decision, which mandates the provision of services in the least restrictive environment possible, several states are exploring the potential of supportive housing<sup>185</sup> as an alternative to costly institutionalization. The supportive housing model evolved as a product of efforts to link normal permanent housing options (e.g., apartments, condominiums, single-family homes) with supports and services needed or desired by the residents. Supportive or service-enriched housing often includes group residences specifically designated for older persons, such as government-subsidized senior apartments, retirement housing, and assisted living facilities. It also can include Naturally Occurring Retirement Communities (NORCs).<sup>186</sup> This community-based approach targets three vulnerable groups that

need long-term supports and services to live as independently as possible: frail elders, people with significant disabilities, and chronically homeless people. Development of supportive housing for these three subpopulations share many common principles, approaches, and issues.<sup>187</sup> These similarities reflect common issues and needs among all three groups, including the following:

- High rates of poverty
- Desire to live in normal housing rather than in segregated and restrictive settings
- The need for long-term supports and services to live as independently as possible
- The desire for personal control, autonomy, and choice

Given these similarities, several models of supportive housing, regardless of the subpopulation they serve, are profiled in this chapter.

Other models of supportive housing specifically targeting people with disabilities emerged from the independent living movement.<sup>188</sup> Nearly 500 Independent Living Centers<sup>189</sup> have been created that provide various combinations of services, such as attendant care, financial assistance, peer counseling, advocacy, referral, transportation, and assistance with housing.

As part of the NFI, the Bush Administration proposed the Medicaid Demonstrations Act of 2003 intended to promote community-based rather than institutional long-term care services for individuals with disabilities and to help states implement the Supreme Court's *Olmstead* decision by providing funding for several demonstration projects. The President's budget proposes \$350 million a year in funding for five years, for a total of \$1.75 billion for a demonstration called Money Follows the Person (MFP) Rebalancing Initiative.<sup>190</sup> The goal of this initiative is to assist states in developing and implementing a strategy to create a more equitable balance between spending on institutional and community-based services and eliminate barriers that Medicaid-eligible people face when choosing to receive long-term care services in the community.

Rebalancing the long-term care system means adjusting the state's publicly funded long-term care supports by increasing the availability of service options in the community and reducing

reliance on institutions so that the supply of available services reflects the preferences of older people and people with disabilities. A balanced long-term care support system increases the amount of control individuals with disabilities are able to exert over service choices.

When “money follows the person,” financing moves with the person to the most appropriate and preferred setting. It is a market-based approach that gives individuals more choice over the location and type of services they receive.

According to the proposed initiative, the Federal Government would pay 100 percent of the cost of a Medicaid-equivalent package of home- and community-based services for Medicaid-eligible individuals who move from a Medicaid-certified institution to the community. The initiative would be assured for five years to give states adequate time to consult with stakeholders, design their plans, and prepare for implementation.<sup>191</sup>

Several states already have been working on rebalancing institutional and community-based care and have undertaken initiatives to enable money to follow the person.<sup>192</sup> They typically use one or more of the following strategies:

- Legislative actions that set a policy of balancing the long-term care system and create budgetary mechanisms to move funding from institutional to home- and community-based services.
- Market-based approaches that offer participants more community supports and timely information.
- Fiscal and programmatic links that improve coordination among different functions in the support system and encourage more community services and less reliance on institutions.

A 2003 report states that about 1.2 million people receive disability-related support services at home through state Medicaid plans or HCBS Waiver programs.<sup>193</sup> Under state plans, services traditionally have been restricted to attendant assistance with personal care and homemaking and/or other services and products determined by licensed care agencies. In contrast to these traditional models, states are increasingly offering Medicaid beneficiaries and their families the opportunity to obtain support services from individual providers. This alternative approach is

termed consumer-directed (CD) care.<sup>194</sup> The Cash and Counseling program is an expanded model of CD support services in which Medicaid consumers with disabilities decide for themselves how their personal assistance needs are met. It provides a flexible monthly allowance (based on the consumer's care plan or on claims history) that consumers can use to purchase a variety of support services. Or beneficiaries may use the money to make home modifications or buy assistive devices that may reduce their future need for personal care. Along with the cash, consumers receive information, advice, and training on how to access and manage their own care. The program requires enrollees to develop a spending plan and provides counseling and fiscal assistance to help consumers manage their allowances.<sup>195</sup>

The initial Cash and Counseling Demonstration Project was launched in 1995 in three states: Arkansas, Florida, and New Jersey.<sup>196</sup> The project was sponsored by the Robert Wood Johnson Foundation (RWJF) and the Office of the Assistant Secretary for Planning and Evaluation in the U.S. Department of Health and Human Services (ASPE/DHHS). A preliminary comparison of the Cash and Counseling CD model with the traditional agency-directed approach to delivering personal assistance services showed that the great majority of consumers in each of the three Cash and Counseling programs were very well satisfied with the program. An evaluation of the effect of the program in Arkansas, the first state to implement Cash and Counseling, showed that Medicaid beneficiaries who had the opportunity to direct their personal assistance services received better care than a control group. They reported higher satisfaction, better quality of life, fewer unmet care needs, better access to home care services, and less nursing home usage,<sup>197</sup> all without compromising the beneficiaries' health or safety and with no greater cost burden to Medicaid than traditional agency services.<sup>198</sup> Because of the success of the demonstration model, in early 2004, RWJF announced a \$7 million grant for the expansion of Cash and Counseling under which as many as 10 states will receive up to \$250,000 each over three years to replicate the CD model.<sup>199</sup>

Following are examples of successful state and locally supported efforts at improving health and long-term care services for people with disabilities and frail elders.

**Minnesota and Wisconsin developed health care delivery systems that have the potential to become national models for delivering services to frail elders and people with disabilities.**

**Their early successes suggest that states can successfully work with prepaid managed care plans to develop tailored programs that enhance the physical and mental well-being of these populations.**

**Minnesota Disability Health Options (MnDHO),**<sup>200</sup> a voluntary program, is a specialized managed care program for working-age people with physical disabilities who are eligible for Medical Assistance (MA),<sup>201</sup> with or without Medicare. MnDHO integrates delivery of all Medicaid and Medicare services. Beginning in January 2005, prescription drugs will be included in the contract. The Minnesota Department of Human Services (DHS) administers the MnDHO program and pays Medicaid capitation to UCare Minnesota, a nonprofit health plan. UCare Minnesota contracts with AXIS Healthcare to provide care coordination, provider relations, and member services. AXIS Healthcare assigns a care coordinator to each enrollee; the coordinator assists the member with accessing and coordinating health care and support services. The coordinator works with the enrollee as a partner to arrange for service provision from doctors, home care providers, health care agencies, equipment suppliers, and transportation providers. In some cases, the coordinator can obtain home modification assistance for enrollees. An AXIS Care Coordinator is available 24 hours a day/7 days a week to triage emergent concerns when they arise.

**Eligibility:** Participation is voluntary. Individuals must be between the ages of 18 and 65, have a physical disability, be eligible for MA, and live in one of the following counties: Hennepin, Ramsey, Anoka, or Dakota.

**Services:** MnDHO offers all MA and Medicare services (for Medicare beneficiaries), including doctor visits, lab and x-rays, emergency care, DME, hospital care, nursing home care, home- and community-based care such as home health care, personal care and attendant services, and transportation to appointments. The health plan also may offer services to waiver eligible members that normally are not covered by MA or Medicare, such as modifications to the home or vehicle, extended personal care attendant services, and others.

**Benefits:** The program began in September 2001 and by October 2004 had 350 members. Slightly more than 50 percent are dual Medicare/Medicaid beneficiaries. Interviews and focus

groups at the end of first year show that 9 of 10 members report satisfaction with their health care services one year after enrollment compared with the prior year. At the same time, hospitalization rates and hospital lengths of stay have been reduced by half or more, which may lead to future cost savings.

For more information, see the DHS Web site at

[http://www.dhs.state.mn.us/main/groups/healthcare/documents/pub/DHS\\_id\\_006272.hcsp#P55\\_3487](http://www.dhs.state.mn.us/main/groups/healthcare/documents/pub/DHS_id_006272.hcsp#P55_3487).

For more information, contact

UCare Complete

Phone: (612) 676-3500

Toll Free: (877) 523-1518

TTY: (800) 688-2534

AXIS Healthcare

Phone: (651) 641-0887

Web: <http://www.axishealth.com>

**Wisconsin Partnership Program**<sup>202</sup> is a comprehensive program of services for older adults and people with physical disabilities in Wisconsin. The program integrates health and long-term support services, and includes home- and community-based services, physician services, and all other health care services. The Department of Health and Family Services contracts with CBOs to implement the Partnership Program. These organizations, in turn, subcontract with hospitals, clinics, home health agencies, residential providers, nontraditional service providers, pharmacies, and other providers to ensure a comprehensive network of acute and long-term care. The Wisconsin Partnership Program combines the benefits of the Medicaid/Medicare systems into one program through an 1115/222 dual waiver,<sup>203</sup> which helps to avoid fragmentation and duplication of services. It provides high-quality, flexible, consumer-centered, comprehensive, and continuous care across settings and providers. It uses a model of service delivery based on collaborative, interdisciplinary<sup>204</sup> teams that collaborate with enrollees on the development of care plans and coordinate all service delivery.

**Eligibility:** Participation in the Wisconsin Partnership Program is voluntary. Individuals must be either age 55 or older (model serving older adults), or age 18 to 65 with a disability (model serving people with physical disabilities) to enroll in the Partnership Program. They must be eligible for Medicaid and meet the Wisconsin Medicaid nursing home level-of-care requirement. Most participants are eligible for both Medicare and Medicaid.

**Services:** A key component of the Partnership Program is team-based care management. Under this arrangement, the enrollee, who is the central figure on the team, his or her physician, a registered nurse, a nurse practitioner, and social service coordinator or social worker develop a care plan together. Other team members may be drawn in as the member's needs change. Participants often keep their own physicians who, in most cases, are added to the Partnership provider network. In addition to comprehensive health care, the services include, but are not limited to, the following: daily living assistance from attendants, physical and occupational therapy, adaptive equipment, assistance in locating accessible housing, housekeeping, transportation to medical appointments, laundry service, prescription medications, and more.

**Benefits:** The Wisconsin Partnership Program allows members to live in their preferred settings, participate in community life, and be engaged in decision making processes regarding their own care. The program uses the cost-containment features of a managed care system and integrates Medicare and Medicaid funding streams and service delivery systems to provide acute and long-term care services. As of September 2004, 1,712 people were enrolled in the Partnership Program at four Wisconsin sites.<sup>205</sup>

For more information, see the Department of Health and Family Services Web site at <http://dhfs.wisconsin.gov/WIpartnership/index.htm>.

## **Supportive Housing Initiatives**

To address the needs of its large population of elders and people with disabilities, Arkansas has developed a comprehensive array of supportive housing and community-based alternatives that allow these groups to live meaningful lives in the community.<sup>206</sup> Two such initiatives are described below.



**The Coming Home Program:** An initiative sponsored by the RWJF<sup>207</sup> and National Cooperative Bank Development Corporation (NCBDC).<sup>208</sup> In January 2001, Arkansas received one of nine Coming Home Program<sup>209</sup> grants to create an assisted living model to serve low-income seniors (including those on Medicaid with incomes at or less than 300 percent of SSI or \$564 per month) by reducing shelter payments to about \$350–\$400 per month and funding necessary support services through Medicaid. The initiative involved combining a comprehensive service package under a Medicaid §1915(c) HCBS Waiver<sup>210</sup> with other available funding sources. To make this demonstration project possible, the Arkansas State Legislature passed the Assisted Living Act (Act 1230 of 2001) that promotes “the availability of appropriate services for elderly persons and adults with disabilities in the least restrictive and most homelike environment” and encourages “the development of innovative and affordable facilities particularly for persons with low to moderate income.”<sup>211</sup> In December 2002, one of the nation’s first truly affordable assisted living facilities,<sup>212</sup> the Gardens at Osage Terrace, opened in Bentonville, Arkansas.<sup>213</sup> All of the facility’s 45 apartments serve Medicaid-eligible individuals and those at or below 60 percent of the area median income. In May 2003, two additional Coming Home assisted living demonstration projects were awarded federal low-income housing tax credits: Fruit of the Spirit in College Station, and Whispering Knoll in Pine Bluff. Both projects will create 40 assisted living units that serve predominantly low-income, Medicaid-eligible elders and will form partnerships with local senior care providers to meet the service needs of the residents.<sup>214</sup>

**The Arc of Arkansas:** Unique housing initiatives that provide quality affordable, accessible housing for Arkansans with and without disabilities. All of The Arc’s housing projects are renovated historic buildings located along regular bus lines that feature universal design standards to attract and accommodate people with and without disabilities. The Arc uses Historic Preservation Tax Credits, grants from the Historic Preservation Trust, and other funding sources to renovate buildings for new housing. Their first project, Trinity Court Place Apartments, a 22-unit independent living facility for low to moderate-income residents with disabilities and their families underwent renovation beginning in 1998. By 2004, The Arc had renovated three properties with 106 rental units. Forty percent of the residents are people with disabilities. For more information about The Arc of Arkansas properties, see Chapter 2 of this report.

**Supportive Housing in Connecticut:**<sup>215</sup> In the past, Connecticut has disproportionately relied on institutions to provide long-term care for both the elderly and younger people with disabilities. More recently, increasing attention has been paid to supportive housing programs for these two populations. Supportive housing programs for the elderly are designed to reduce reliance on institutional care by delivering services to frail elders, who, without such assistance, would need to relocate to a nursing home. Supportive housing for nonelderly people with disabilities reflects a broader range of strategies that emphasize autonomy and inclusion in the community. Several of these initiatives received recognition for their creative financing approaches involving both capital and subsidy funding to create permanent, service-rich housing for low-income people with disabilities. Highlights of two programs for the elderly, followed by two programs for younger people with disabilities, are presented below.

- **Assisted Living Services (ALS) in State-Subsidized Congregate Housing:**<sup>216</sup> All state-subsidized elderly congregate housing (CH) facilities are eligible to participate in the ALS program, which is designed to offer services to frail elderly residents who meet the functional eligibility requirements for the state home care program. The addition of the ALS program in participating CH facilities offers frail CH residents access to instrumental and personal care services, which are provided by the staff from an Assisted Living Services Agency (ALSA). Eligible residents participating in the ALS program receive a package of services based on individualized care plans. The ALS program provides services that are not part of the existing service package in CH. These services include personal care assistance, medication supervision, shopping, homemaking, laundry, and other services. Funds for the ALS program come from either the Connecticut Home Care Program for Elders (CHCPE) or a Department of Economic and Community Development (DECD) subsidy that provides up to \$500 for residents who are income eligible for the CHCPE but exceed the asset limits. As of June 30, 2003, a total of 269 residents received ALS.
- **ALS in Federally Subsidized Senior Housing:**<sup>217</sup> Four federally subsidized senior housing complexes were authorized under legislation passed in 2000 and 2001 to provide ALS under the state's Medicaid waiver program. Three complexes are currently operational. Of these, two provide the additional subsidy for elders who are not eligible

for the CHCPE. As of June 30, 2003, a total of 150 residents received ALS under this program.

- **New Pilots Supportive Housing Initiative:**<sup>218</sup> Authorized in 1998, this initiative is designed to develop a range of supportive housing options across the state with two strategies: (1) to add services to existing private apartments, and (2) to develop new units. This demonstration involves the cooperation of more than 50 public and private agencies and, ultimately, a goal to provide 650 units of service-supported housing serving a mix of formerly homeless people and families and individuals with disabilities. In addition to the Connecticut Housing Finance Authority (CHFA), which reviews and oversees the projects, other state agencies in the project include the Department of Mental Health and Addiction Services (DMHAS), Department of Social Services (DSS), and DECD. Private foundations, local developers, and service providers have cooperated to develop an array of housing and services. Housing units may come from new construction, rehabilitation, acquisition, or leasing of scattered sites. Case management is considered the key to providing individualized services. Services include independent living skills training, employment training, peer supports, and links with other community services. In 2000, during Phase I of the Pilots Program, Connecticut allocated \$2.1 million for services provided through the DMHAS. With these funds, DMHAS funded 50 service providers. For several projects, the funding for services provided by the state served as a match to secure rental subsidies through the HUD Continuum of Care Program. During Phase 1, 200 supportive housing units were created in existing housing. In 2001, 100 additional units were added by converting private apartments to supportive housing. During this time, Connecticut allocated an additional \$3 million for service subsidies and set aside a \$23 million financing package (e.g., Low-Income Housing Tax Credits) to fund the construction of 300 to 350 new units of additional supportive housing. In 2003, \$6 million was added to the DMHAS and CHFA budgets to cover the expenses of expanding the program. The overall goal of the project, when complete, is to provide affordable, integrated supportive housing for up to 570 people with disabilities who will live together with others in the community.
- **CMS System Change Grants: Nursing Facilities Transition and Community Integration:**<sup>219</sup> Connecticut is the recipient of two CMS System Change grants designed

to enable people with disabilities to live in the least restrictive environment possible. These System Change initiatives are designed to facilitate the integration of people with disabilities into the community. In 2001, Connecticut received a three-year \$800,000 grant to facilitate the transition of 150 nursing home residents into the community. The Connecticut Association of Centers for Independent Living is responsible for carrying out the project's major activities. To date, a total of 40 transitions have been successfully completed.

**The New York City Naturally Occurring Retirement Communities/Supportive Service Programs (NORC-SSPs):**<sup>220</sup> In this model, partnerships among housing providers, residents, social service providers, government agencies, and philanthropic organizations are formed to assess the needs, interests, and resources of a community and its residents. After the assessment, the partnerships organize a range of coordinated health care and social services for the residents that are delivered on site. Most NORC-SSPs are located in high-rise apartment buildings. As of June 2000, 28 NORC-SSPs were serving communities and housing developments in four of New York City's five boroughs, where more than 46,000 seniors live. Eligibility to receive services and participate in programs is based on age and residence in the NORC, not on functional or economic status. Services are flexible and responsive to needs and interests identified by the residents. The New York NORC-SSP model consists of four core services: (1) a range of individual social work services;<sup>221</sup> (2) health-related services and programs;<sup>222</sup> (3) education and recreation activities; and (4) volunteer opportunities for the seniors in the community.

New York City's NORC-SSPs are financed through public-private partnerships and in-kind supports. The almost \$5 million of state and city government funding constitutes more than half (56%) of total funds available and is the base on which additional funding is leveraged. Private sector funding comes from a variety of sources that include the housing corporation (10%); health care providers' in-kind contributions (13%), philanthropy (17%), and various membership fees and local fundraising efforts (4%). This NORC-SSP model is gaining increasing attention within New York and throughout the nation.

## **Chapter 7: Encourage Participation in Civic, Cultural, Social, and Recreational Activities**

Rick Canen worked for the Steelcase Corporation in Grand Rapids, Michigan, for 30 years—first in the factory and later, when his sight failed, in the company’s cafeteria. Rick is retired now, but he seems busier than ever. He is a member of several advocacy groups in Grand Rapids, including Concerned Citizens for Public Transportation and Faith in Motion,<sup>223</sup> and is involved with several different organizations for the blind, including Pilot Dogs, a nonprofit organization founded in 1950 to train guide dogs and teach blind people to work with them. Diabetic since he was nine years old, Rick eventually lost his sight and needed a guide dog himself. Three years ago, Freedom, a Labrador retriever, came to live with the Canens. Rick is very fond of Freedom and calls her an “ice-breaker” that helps him do research about peoples’ transportation needs. “I ride the bus to pick up information from riders about how well our transportation system works for them.” On the bus, Freedom attracts people’s attention and helps Rick start conversations about bus service and other community transportation issues. Rick and Freedom also visit schools, where Rick talks to children about guide dogs, and they attend drivers’ education classes where Rick teaches budding drivers about the White Cane Law—a law that specifies rules for yielding to pedestrians with canes or guide dogs.

Recently, Rick added yet another activity to his already full schedule. He and about a dozen other people, most with disabilities, signed up for “Utter Words,” a communications and leadership group modeled on the format pioneered by the famed nonprofit organization, Toastmasters International.<sup>224</sup> Weekly meetings held at Disability Advocates of Kent County allow participants to practice their public speaking skills and receive constructive criticism from the group’s coordinator and fellow participants. Rick and many of the others joined the group to learn how to translate their passions about disability-related and other issues more effectively into messages that capture the attention of legislators. “You’ve got to boil the message down to three to five minutes, otherwise you lose them,” explains Rick. In addition to being a transportation advocate, Rick feels strongly about the need for “money to follow the person” when it comes to health care, and he has already been to the state capital to present a case for shifting long-term care dollars from nursing homes to home- and community-based care. With

additional public speaking training, Rick feels he'll be able to deliver the messages even more effectively.

Rick considers himself a voice for all the people who are unable to go to meetings and be their own advocates because they have to work to support themselves. "Even if I can make a little dent in transportation and other policies, maybe these people won't have it so hard in the future," he says. "When I was working, I didn't have a lot of time for these issues, so I made it my retirement goal. Many people helped me when I was working. Now it's time for me to go out and give back to the community."

The 2000 N.O.D./Harris Survey of Community Participation was an online survey of 535 people with disabilities and 614 people without disabilities. The survey asked respondents about the extent of their participation in a variety of community activities and whether they felt connected to or isolated from the communities in which they live. One theme to emerge from the survey findings is that, overall, "people with disabilities feel more isolated from their communities, participate in somewhat fewer community activities, and are less satisfied with their community participation than their counterparts without disabilities."<sup>225</sup> When compared with people without disabilities, people with disabilities are almost twice as likely to say they are isolated from others and one and one-half times more likely to say they are "left out of things" in their communities. When asked how involved they are in their communities, 35 percent of people with disabilities say they are "not at all involved," compared with 21 percent of people without disabilities. While people with disabilities and people without disabilities seem to have a similar degree of knowledge about how to become involved, people with disabilities are significantly more likely than people without disabilities to say that they never participate in religious services, local politics, and cultural events.<sup>226</sup>

According to the 2000 N.O.D./Harris Survey of Community Participation, low rates of participation among people with disabilities is due, in part, to the lack of encouragement from community organizations: "While approximately half of people with disabilities (and more than 6 out of 10 people with severe disabilities) agree that community organizations have not reached out to them to participate, only 35 percent of people without disabilities say the same."<sup>227</sup> One

implication of these findings is that community organizations “need to take a different, more concerted approach to reaching out to this group, in particular those with severe disabilities.”<sup>228</sup>

A community hardly can be called livable for people with disabilities if they do not feel part of the social fabric and are not involved in the community’s civic, cultural, or social activities. As the survey results suggest, it is not enough for community organizations to simply offer such activities and provide information about them. To be truly inclusive, community organizations must actively encourage the participation of people with disabilities.

The community-based programs profiled in this chapter were chosen not only because they actively reach out to people with disabilities, but also because they make integration one of their primary goals. A community where people with disabilities routinely work, play, learn, and worship alongside people without disabilities is a livable community indeed.

**In Phoenix, Arizona, outdoor recreational activities are accessible—and exciting—for people with disabilities.**

Since 1973, the City of Phoenix Parks and Recreation Department’s Adaptive Recreation Services section has provided year-round, inclusive recreational programs for children, teenagers, and adults with disabilities.<sup>229</sup> For example, River Rampage<sup>230</sup> is a whitewater rafting trip for eight teenagers with disabilities and eight at-risk teenagers. River Rampage receives additional support from River of Dreams, a nonprofit organization, and recently completed its eleventh year of operating three trips per summer.<sup>231, 232</sup>

The Department’s newest program is Daring Adventures, an outdoor recreation program for teenagers and adults with and without disabilities.<sup>233,234</sup> Although some activities require enrollment fees, participants have the option of providing volunteer service hours in lieu of fees. Daring Adventures adaptive programs include the following:

- Adaptive cycling consists of handcycles for people with mobility impairments and tandem bicycles for people with visual impairments. Participants meet for 1.5 hours every week

for six weeks to get accustomed to the handcycle or tandem bicycle, and are then eligible to rent them on their own.

- Adaptive kayaking consists of one- and two-person “sit-on-top” kayaks for people with visual or mobility impairments. After completing a six- to eight-week instructional program consisting of four hours per week, participants can rent kayaks on their own.
- Sled ice hockey involves adjustable adaptive ice sleds that can be used by all people with disabilities. Three 8- to 10-week sessions with one hour of ice time per week are offered. Two different ice rinks are used, one in Peoria and one in Scottsdale. The City of Peoria contributes ice time for one of the sessions, while the City of Scottsdale provides support for some of the staff.
- For cross-country skiing, skis with Velcro straps for the waist, ankles, and knees and shortened ski pulls are available for people with mobility impairments. A six-week program of conditioning exercises followed by a weekend stay in Flagstaff is offered twice a year. Cross-country skis are available for people with other types of disabilities. The slopes have two sets of parallel tracks, enabling a sighted person to ski alongside a visually impaired skier.
- Hiking and backpacking is a new offering. The program, which is in its beginning stages, will start with recreational hikes along routes with little change in the terrain. Eventually, guided hikes of various lengths and difficulties will be offered for all people with disabilities. Hiking wheelchairs and assisted hiking chairs are available to program participants.
- Wilderness camping trips take place at Camp Colley, a three-hour drive northeast of Phoenix. The program uses a camp area that has three platform tents with ramps that are wheelchair accessible and two accessible portable toilets. Two camping trips were completed in 2004.

Researchers at Arizona State University are compiling information about program participants and estimate that close to 400 people have participated in Daring Adventures programs, 80 percent of whom were people with disabilities.



Daring Adventures was funded by a three-year grant from the U.S. Department of Education, beginning in October 2001 and slated to end September 2004. The grant supported a full-time coordinator and equipment, with the City's Adaptive Recreation Services supporting the remaining staff. The program will continue through June 2005 because of the availability of funds resulting from a vacated position. Plans are under way to seek additional funds to extend the life of the program. Feedback from participants has been very positive.

For more information, see the City of Phoenix, Arizona, Web site at <http://www.phoenix.gov/PRL/dadv.html>.

For more information, contact

Linda Tuck

Phone: (602) 534-5683

Email: [linda.tuck@phoenix.gov](mailto:linda.tuck@phoenix.gov)

**The Experiential Education Initiative at the John F. Kennedy Center for the Performing Arts is an opportunity for young people with disabilities to learn about the arts alongside their peers without disabilities.**<sup>235</sup>

The John F. Kennedy Center for the Performing Arts' programs integrate people with and without disabilities in two artistic internship programs. The Experiential Education Initiative (EEI)<sup>236</sup> is an internship program for young adults with cognitive and developmental disabilities, funded by the Connors Foundation;<sup>237</sup> the Vilar Institute for Arts Management Internship is for college-age students (see Table 3).

The selection criteria<sup>238</sup> for the two internship programs are different, but the types of assignments and the job requirements are virtually the same. Placements have included assignments in administrative and artistic departments of the Kennedy Center, including the Youth and Family Programs, the Eisenhower Theater, the National Symphony Orchestra library, gift shops, the volunteer office, and the Finance and Human Resources departments. Placements are designed to help young people experience performing arts-related careers beyond the more

obvious roles of performer or artist; examples of past positions held by interns include graphic designer, Web coordinator, and grant writer.

To foster group cohesion, the number of EEI interns is kept intentionally smaller than the number of Vilar interns. All of the interns are required to submit weekly journals based on their internships, receive the same stipend, and attend the same seminars, social events, and performances.

Technically, both groups have a 40-hour work week, but EEI interns usually spend 20 hours in their assigned roles because they are required to attend performances and their transportation time, which can be significant, is included in their work week. In addition to developing work skills, priorities for the EEI interns include exposure to the arts and development of social skills.

| <b>Table 3.</b> Selection criteria and job requirements for interns enrolled in the EEI and the Vilar Institute for Arts Management Initiative at the John F. Kennedy Center for the Performing Arts. |   |  |
|---|---|--|
|   | <b>EEI</b>                                    | <b>Vilar</b>   |
| <b>Admission</b>  | Referred and prescreened by service providers | Competitive application  |
| <b>Semester</b>   | Fall or winter                                | Fall, winter, or summer  |
| <b>Interns per semester</b>   | 3   | 20–25  |
| <b>Age group</b>  | 21 to 30 years                                | College juniors/seniors, graduate students, or recent college graduates (within two years) |
| <b>Attendance at Kennedy Center performances</b>  | Required (minimum of 2 per month)             | Encouraged   |
| <b>Attendance at social events for interns</b>  | Encouraged                                    | Encouraged   |
| <b>Weekly journals</b>  | Required                                      | Required   |
| <b>Attendance at weekly seminars with upper level management</b>  | Required                                      | Required   |
| <b>Stipend</b>  | \$800/month                                   | \$800/month  |

Betty Siegel, Manager of Accessibility at the Kennedy Center, believes that the program may affect future patterns of hiring people with disabilities in arts-related careers. Exposure to EEI

interns already has had a positive effect on departments at the Kennedy Center, and some have been specifically requesting EEI interns. Siegel believes that current Vilar interns, who will be the arts managers of tomorrow, will be inspired by their positive experiences with their EEI colleagues to hire people with disabilities in the future.

Two stories illustrate the successes that have been achieved since the internships were first available in 2001:

**Example 1:** EEI interns are admitted to the program through referrals from service providers, which means that the EEI department is unaware of an intern's skills until he or she begins working. As a result, restructuring of assignments may be necessary. For example, when an intern who did not know how to read arrived, his responsibilities were shifted so that his main task was ushering at the Millennium Stage Performances. The intern's supervisor showed a high level of commitment to the objectives of the program when he assumed responsibility to teach the young man to read using the book on which the play was based.

**Example 2:** J.P. is an adult with Downs syndrome who was unhappy in his job bagging groceries, his only job since leaving school.<sup>239</sup> The opportunity to participate in EEI was a dream come true for J.P. because it allowed him to combine working with his love of theater. J.P.'s internship began in the Youth and Family Program, which stages theater for young people. As part of his job, J.P. made sure that the young performers were ready to go on stage when needed. J.P. learned the duties of a rehearsal assistant, as well as office tasks such as data entry and filing. J.P. particularly enjoyed ushering and applied for a permanent position as an usher at the Kennedy Center when it became available. J.P. went through the regular application and training process—the combination of his theatrical background and self-confidence in social situations landed him the job.

For more information, contact

Betty Siegel

Manager of Accessibility at the Kennedy Center

Phone: (202) 416-8727

Email: [access@kennedy-center.org](mailto:access@kennedy-center.org)

**AXIS Dance Company is paving the way for a powerful and inclusive dance form called “physically integrated dance.”<sup>240</sup>**

Since 1987, the AXIS Dance Company has been performing a body of work developed by dancers with and without disabilities. When Judith Smith became artistic director in 1997, she felt that integrated dance was not getting the attention it deserved. She also observed that people were unsure whether AXIS was providing art or therapy, so she commissioned external choreographers to create dance pieces for the group, which resulted in legitimizing integrated dance and improving the quality and visibility of the work.<sup>241</sup> Smith found that the commissioned choreographers gained something valuable from their experiences with the company as well. Integrated dance has provided an entirely new palette of movement and possibilities for icons in the dance world such as Ann Carlson, Bill T. Jones, and Stephen Petronio.

The company consists of a dedicated group of dancers, performers, and administrators; some juggle all three roles. Roughly half of the seven core dancers dance on two legs; the other half use wheelchairs or crutches. Some danced before acquiring their disabilities; others grew up with disabilities and found dance later in life. The company has created more than 30 repertory works, 2 evening-length works, and 2 works for young audiences. Based in the San Francisco Bay area, AXIS performs at major dance venues around the country and nationwide<sup>242</sup> and has won numerous awards and honors for its work.<sup>243</sup>

AXIS spends roughly half of its time conducting education and outreach activities in the Bay area and on tour.<sup>244</sup> In 2003, AXIS served approximately 18,000 people, many of them schoolchildren. The AXIS education and outreach program, entitled “Dance Access,” creates residencies for youth and adults with and without disabilities and provides opportunities to experience the Dance Company in a variety of ways, including the following:

- Adult Classes and Workshops—AXIS teaches a variety of dance disciplines,<sup>245</sup> offers master classes and teacher training for concentrated study, and directs “performance labs,” which provide an opportunity for community members of different ages, backgrounds, and abilities to design and create a dance piece for presentation at various community settings.
- Youth activities—“Dance Access/KIDS” entertains and educates about dance, disability, diversity, and inclusion. Classes emphasizes children’s creativity while encouraging cooperation and communication. AXIS also conducts in-class presentations and 30- to 40-minute performances with questions and answers for groups in schools or in the theater.
- Performances—AXIS tailors their performances to specific needs and offers professional full-length performances or less formal events. The company can travel with the full ensemble or with a smaller group, presenting shows ranging from 30 to 90 minutes.
- Lecture Demonstrations—Lecture demonstrations, including video presentations, slides or other media aids, and short physical demonstrations, are designed for venues that lack the space or resources for a performance or workshop but are interested in learning about AXIS.
- Pre- and Post-Performance Q&As—Question and answer sessions give audiences an opportunity to provide feedback to the dancers about their work, and to discuss choreography and dance and disability issues.

AXIS is supported by earned income from performances and outreach and education work, and receives support from government sources, private foundations, and individuals.<sup>246</sup>

For more information, see the AXIS Dance Company Web site at <http://www.axisdance.org>.

**FaithWays is hard at work dispelling the stigma and isolation of mental illness by helping Minnesota’s faith communities become truly inclusive and caring.**

“The faith community is in a unique position to fight stigma and isolation, and also to spread a message of faith and hope,” says Mary Jean Babcock, director of FaithWays,<sup>247</sup> a grassroots

organization that is part of the Minnesota Chapter of the National Alliance for the Mentally Ill (NAMI). Babcock explains:

It is not only people with mental illness themselves, but also their families, that tend to isolate themselves. Faith communities can bring issues out into the open, and by doing so they can provide a place where families truly feel accepted and valued. Faith communities are on the frontline. If people can find acceptance there, it can go a long way to help them gain acceptance in other parts of society.

FaithWays has worked throughout Minnesota since 2000, providing customized education programs and assistance on a wide variety of mental health issues to congregations in many, mostly Christian, denominations. Recently, they have begun to work with the Buddhist community as well. Another organization, the Mental Health Education Project, is a similar collaborative effort of the Jewish community of Minneapolis and Saint Paul, Minnesota.

FaithWays is designed to help congregations understand mental illness and become more accepting of people with mental illness. Its education program, “Breaking Down Barriers and Building New Foundations,” is specifically designed for faith communities. Individuals tell of their personal experiences with particular mental disorders to dispel myths and inform audiences about treatment and community resources. FaithWays helps link congregations to each other and to mental health agencies, and provides direct technical assistance to congregation staff, religious educators, caregivers, and volunteers as they work toward creating more inclusive faith communities. It has held a conference on brain disorders, which was tailored specifically to the faith community.

Usually, FaithWays is approached by a member of a congregation—such as a family member of a person with mental illness or a congregation staff person such as a parish nurse—for help. FaithWays then evaluates the community’s needs and provides programming to respond to those needs. Members of the congregation are often inspired to carry on after the programming has ended. For example, after the Hosanna Lutheran Church in Forest Lake, Minnesota, hosted a speaker from FaithWays’ parent agency, NAMI, Kathy and Dave Okeson began a support group for family members of people with mental illness. “My husband and I have children with mental

illness,” says Kathy Okeson, “we have received a lot of encouragement from our church, and we wanted to create a network in which family members can share information and resources, and offer comfort to each other during difficult times.” Kathy and Dave both received facilitators’ training, and attended a 12-week course called “Family to Family” offered by NAMI. The support group is thriving, and over half of the group’s attendees are now from outside the congregation. Other congregations have institutionalized mental health advisory boards. One congregation’s youth group took on mental illness as their “social justice issue” for the year. “Aside from helping parishioners find help and acceptance,” says Babcock, “FaithWays’ work also dispels misconceptions about mental illness and helps people become more aware and more supportive community members.”

For more information, contact

Mary Jean Babcock

Director, FaithWays Program, NAMI-MN

Phone: (651) 645-2948, extension 107

**In Harris County, Texas, voting has been made easier for people with and without disabilities with a state-of-the-art, user-friendly, electronic voting system.**

Harris County, the largest county in Texas and the third-largest county in the nation, fully implemented the eSlate™ Electronic Voting System in November 2002. The system is accurate, secure, and accessible to all voters, including people with visual impairments and/or mobility impairments.<sup>248</sup> It is programmed with English, Spanish, and Vietnamese languages and has the ability to add other languages.

The eSlate™ device is about the size of a legal pad, 1 inch thick, and weight 5.2 pounds. Voters use a rotary wheel to navigate through the ballot and select their vote by pushing an “ENTER” button when their selection is highlighted. The system does not allow voters to select more than the allowable number of choices in a single race, but does allow voters to make changes to their ballots and to skip individual races if they so choose. After voters have entered their selections, the system presents a summary of the voter’s selections, which indicates skipped races and

allows voters to verify their votes and make changes or corrections. After reviewing the summary page(s), the voter must press the “CAST BALLOT” button and an American flag icon appears on the screen, indicating that the vote has been cast and counted.

The rotary interface makes eSlate™ more accurate and durable than touch screens. The eSlate™ system records each vote, tabulates vote totals, and reports and archives results. All votes are private and cannot be traced to individual voters. As a security measure, the “logic and accuracy testing” process, whereby the system programming is tested and validated before and after each election in front of witnesses, is used to ensure that votes are counted and reported as they were cast.

The eSlate™ system is completely ADA compliant and accommodates various devices that support voting by people with disabilities. The system has a special interface for people with mobility impairments, including movable buttons that can be used as an alternate method of navigating the ballot and casting votes. The system also accommodates breath-control devices, known as “sip and puff,” so that people with severe mobility impairments can vote. For people with visual impairments or who have difficulty reading, the system has an audio ballot reader. While the system is designed for independent use, in-person help is available for anyone who requests it at polling places.

In 1998, Beverly Kaufman, the Harris County clerk, established a task force to explore a voting system that would replace the aging punch-card method. The county evaluated several options and postponed purchasing a new system until the technology was more advanced. In 2001, limitations with the ability of the older punch-card voting system to accommodate the length of Harris County’s ballot—as well as the existence of state legislation requiring any Texas-acquired voting system to allow independent voting by people with disabilities—spurred Harris County to act. So, in 2001, Kaufman appointed a second task force,<sup>249</sup> consisting of government, community, and business leaders, and issued a request for proposals from vendors with electronic voting systems approved by the Texas Secretary of State. The task force reviewed the proposals, met with the companies, and held community demonstrations before selecting the eSlate™ Electronic Voting System, a product of Hart InterCivic, Inc.<sup>250</sup> Harris County spent



more than \$25 million on the countywide electronic voting project, including the equipment, long-term support services, and a comprehensive voter outreach and education campaign.<sup>251</sup>

The eSlate™ Electronic Voting System was phased in with “Early Voting”<sup>252</sup> during the November 2001 election and the March 2002 primaries, and was fully implemented by the November 2002 general elections. On November 5, 2002, more than 650,000 voters used the eSlate™ system in each of 720 polling locations throughout Harris County and in 30 early voting locations with little or no difficulty.

For more information about the eSlate™ Electronic Voting System, see the Harris Votes Web site at <http://www.harrisvotes.org/index2.htm>.



## **Chapter 8: Putting It All Together**

In previous chapters, we presented a variety of examples of states, counties, and local communities that have been working toward becoming more livable for people with disabilities and older people in the areas of housing, transportation, the physical environment, employment, health and support services, and social and civic engagement. We included descriptions of several federal regulations, programs, and incentives that have facilitated state, county, and local community action to address issues in each of these six areas. While a number of communities have made great strides in one or even several of these areas and have many successes to report, no single community that we know of has accomplished all there is to do in each category.

By and large, communities that strive to be more livable for the elderly and people with disabilities—and everyone else, for that matter—struggle with obstacles that limit what is achievable. Scant resources or funding “silos” that restrict how funds can be used; few incentives for cooperation or collaboration among agencies and others in the community; lack of support from the public or the Federal Government are just some of the complaints from our sources. But as many of the examples in this report show, communities often find creative ways to overcome obstacles and make progress despite constraints.

### **Strategies and Policy Levers to Affect Change**

If there is one action we can point to that helped many, if not most, of the initiatives profiled in this report become successful, it is the formation of strategic partnerships that worked together to achieve the following goals:

- Leverage resources,
- Address consumers’ needs in a coordinated and comprehensive manner,
- Reduce fragmentation in the service delivery system,
- Provide choice, and
- Implement policies and programs that help people remain independent and involved in community life.

This is, in fact, the principle underlying the San Mateo Strategic Plan—a description of which starts on page 142—and the San Mateo community’s efforts to improve quality of life for elders and people with disabilities in their county. More than a decade ago, several agencies in San Mateo formed a partnership to blend these two populations and create one strategic plan that addresses the preferences and needs of both. The process of developing the strategic plan involved a wide range of community stakeholders to ensure that its goals and objectives represented the vision and mission of constituent agencies, as well as the aspirations and needs of the people it was designed to serve. Since its inception, the strategic plan has been the county’s roadmap for improving its service delivery system to increase quality of life for elders and people with disabilities, and progress is monitored on a monthly basis.

In addition to the important step of developing strategic partnerships, communities profiled in this report have employed four other broad strategies and policy levers that serve as recommendations to other communities planning to expand access to affordable housing, transportation, and employment opportunities; make the built environment more accessible; reconfigure health and support service delivery systems to be more in line with the needs of the populations served; and promote their social and civic engagement.

As the examples contained in this report show, these four strategies can and should be used at every level of government—including federal, state, county, and local—to affect change in any or all of the areas included in our Framework of a Livable Community for Adults with Disabilities:

**Strategy 1. 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. An example of this strategy is San Mateo’s folding of the Area Agency on Aging into the Aging and Adult Services Division, which is part of the county’s Health Services Department. As a result, the county’s various programs for adults are housed under one roof, and the Division’s Team Insuring Elder Support TIES Line—a centralized, toll-free information and referral

telephone line—is available 24 hours a day to help adults enter and navigate the entire county’s health and support services system.

Another example is STAR—the Sweetwater County, Wyoming, public transportation authority—that replaced a number of disparate health and human services agency-based transportation services. STAR pools funds from more than 10 sources and uses a centralized dispatch system to provide coordinated public transportation that serves people with disabilities and the general public in a rural environment.

**Strategy 2. Use tax credits and other incentives to stimulate change in individual and corporate behavior and encourage investment in livable community objectives.**

This strategy often is used to encourage affordable housing development and to reduce the tax burden on individuals. For example, housing programs, such as Austin’s SMART Housing Initiative, provide financial incentives for private construction of affordable housing. The initiative gives housing authorities first dibs on surplus city property at below market prices to encourage construction of reasonably priced homes. Tax policy that helps elders and people with disabilities stay in their homes is exemplified by the Virginia Real Estate Tax Relief Program for Elderly and Disabled Persons, which helps thousands of Virginians reduce their housing costs so they can remain in their community.

Tax credits and other incentives, such as matching funds, can be used to urge employers to hire people with disabilities and encourage the private sector to make their businesses more accessible to elders and people with disabilities.

**Strategy 3. Provide a waiver or other authority to help communities blend resources from multiple public funding streams to provide and coordinate different services.**

Some of the best examples of this policy lever can be found in the health and support services Chapter 6 of this report. There are a number of federal- and state-led initiatives that use Medicaid waivers and other mechanisms to blend funding streams; increase the availability of home- and

community-based services as an alternative to institutional care; support comprehensive, CD care; and generally help states avoid costly fragmentation and duplication of health care services.

#### **Strategy 4. Require or encourage a private sector match to leverage public funding and stimulate public-private sector partnerships.**

Several of the initiatives profiled in this report depend on public-private partnerships to provide services to elders and people with disabilities. The New York City NORC-SSPs, for example, are funded through grants and/or in-kind contributions from state and local government, housing and social service providers, philanthropic organizations, and others to provide support services in areas where a critical mass of older people lives.

Another example is the Texas Home of Your Own Coalition (Texas HOYO), which brings in multiple partners from the private and public sectors—including realtors, lenders, and state and local housing organizations—to help people with disabilities through every step of the process of home ownership.

### **Lessons Learned and Recommendations**

The community initiatives described in this report constitute only a fraction of all the efforts under way throughout the United States to make communities more livable for elders and people with disabilities. Despite many obstacles, these communities have mobilized political will and taken action toward this goal. A number of lessons can be gleaned from the initiatives profiled in this report, many of which can serve as recommendations to other communities that are planning to make greater livability a priority.

#### **Provide affordable, appropriate, accessible housing**

- The lack of a coherent, comprehensive federal housing policy coupled with the dizzying array of disparate housing programs and agencies that have no relationship with one another make navigating the housing landscape a daunting prospect for all but those who are “in the know.” To break through this maze, it is important for the disability and aging communities to build strong partnerships with the “affordable housing” community—an

alliance that traditionally has not been emphasized. Knowledge about and creative use of all affordable housing programs is necessary to expand rental housing programs or homeownership. The Arc of Arkansas, for example, was able to draw on a variety of sources, such as the Arkansas Development Finance Authority HOME program, the Federal Home Loan Bank, Historic Preservation Tax Credits, and a Landmark Grant from the Historic Preservation Trust to renovate old buildings to provide new housing for their target populations.

- Financial incentives for private construction of affordable, accessible housing that is close to public transportation, as well as incentives for setting aside a portion of newly built or renovated units for lower-income individuals, are essential to increase affordable housing options in some communities. Such incentives should be actively promoted and perhaps made even “sweeter” in areas where lack of affordable housing is a critical issue.
- Increasing awareness among consumers about universal design principles and promoting universal design and accessibility features among urban planners and builders will go a long way toward making communities more livable for everybody. The cost of retrofitting a house or the built environment is substantially higher than the cost of including accessibility features in the first place. The Irvine, California, public education efforts about the benefits of universal design could serve as a model for other communities.

### **Ensure accessible, affordable, reliable, safe transportation**

- One of the key informants interviewed for this report said that transportation is more than trains, buses, and cars—it is “an engine for economic prosperity that benefits everyone.” When even one segment of the population has limited access to transportation, it is denied considerably more than just a ride. Seen in this light, transportation must play a central role in any discussion about community livability.
- Like housing and health care, the transportation system involves multiple, disparate resources that sometimes overlap and other times leave big gaps in service. And like housing and health care, transportation is a big issue in most U.S. communities. Judging from the community examples featured in this report, coordinated public transportation systems that unite disparate services and funding streams to create more efficient, cost-

effective, and universally accessible transit systems are more likely to provide choices and, therefore, meet the needs and preferences of people with disabilities, older people, and most everyone in the community. Consumer choice, in fact, is a key component of a good transportation system—choice in available modes of transportation as well as choice in where, when, and how people are picked up and dropped off. Mr. Boger’s story at the beginning of this report is a perfect illustration. He has three transportation options at all times—paratransit service, public bus service, and taxi service—all of which are accessible just outside his front door.

- Centralized computer and dispatch systems that handle all registration, reservations, scheduling, route building, and billing make paratransit and other on-demand transportation systems more efficient and less frustrating for consumers.
- Advanced technology, such as personal digital assistants and global positioning systems (GPS), has the potential to assist people with disabilities and others in navigating a community’s thoroughfares and transportation options. New uses for such technology—as the BrailleNote GPS system described in this report illustrates—should be explored and encouraged.

### **Adjust the physical environment for inclusiveness and accessibility**

- As one of our key informants—an architect and disability specialist—said during our interview, “When people are sensitive to access issues for people with disabilities, they are more willing to do things to improve the environment.” Some of the communities profiled in this report have instituted such “sensitivity training” for employees of local government agencies with very positive results. Such training should be expanded to include the general public—having to confront access problems on a personal basis is an eye-opening experience.
- In communities where accessibility is a priority—like in Nashville, Tennessee, where the mayor made it his personal mission to build and improve the sidewalks of the city and county—a noticeable impact is made on the environment. But city planners, who could have a huge impact on accessibility by educating local government officials and including it as a priority in their plans, are not always aware that access is a problem in their



communities. Sensitivity training can help, but including disability issues in urban planning curricula—which currently gloss over such issues—could be a more effective technique.

- Policymakers have another avenue at their disposal to accelerate improved access to the built environment in their communities: variances to zoning ordinances. In some communities, adherence to strict zoning laws renders it nearly impossible to make accommodations, while in others the mood is more relaxed. The city of Portland, Maine, for example, is fairly lenient in granting variances, and Portland has a national reputation for being a “disability-friendly” city.

### **Provide work, volunteer, and education opportunities**

- Technology is changing the nature of work today, and it has the potential to help expand work opportunities for people with disabilities in several ways: (1) by facilitating education/training programs to help people enhance their skills; (2) by providing “telework” opportunities so that people can work remotely if they wish; and (3) as the Eastern Shore Business Leadership Network’s Web site demonstrates, by providing a means to match qualified job candidates with employers.
- An education campaign for employers to increase awareness about the value of employing people with disabilities could help increase employment opportunities for people with disabilities. As many of our examples demonstrate, when an organization employs a person with a disability, as a regular employee or as an intern, the employer generally is pleased with the results and feels that that the employment benefited the organization as much as the employee.
- To set an example for the private sector, federal, state, and local government agencies need to serve as “model employers” and increase the number of people with disabilities who work in their agencies. In addition, businesses owned by people with disabilities should be promoted throughout government agencies. Through its “Procurement and Entrepreneurial Workgroup,” for example, Chicago demonstrates its commitment to increasing the number of businesses owned or operated by people with disabilities that are certified to participate in procurement programs offered by city agencies.

- Communities can help businesses make reasonable accommodations for employees with disabilities by providing them with funding and/or technical assistance. The “Chicago as a Model City Workgroup,” for example, set up a Reasonable Accommodation Account to help city departments defray the costs of making reasonable accommodations and provide them with technical assistance. This accommodation could be extended to the private sector as well, because the vast majority (90%) of workplace accommodations cost \$500 or less.
- The private sector must take the lead in expanding work opportunities for, and promoting the hiring of, people with disabilities. When Maryland’s Salisbury Area Chamber of Commerce sponsored a business leadership network to increase work opportunities for people with disabilities, it legitimized the mission and drew in its network of 4,000 businesses and organizations, significantly increasing the pool of potential employers.
- Any remaining disincentives to work—such as the prospect of losing health care, Social Security benefits, or other entitlements—need to be removed so that people with disabilities are not penalized because they want or need to work.

### **Ensure access to key health and support services**

- People with disabilities, like all people, prefer to live at home and receive health care and support services in their communities. But, given the current health care financing structure and the fragmentation in the service delivery system, serving people in community settings is a challenge. Despite these obstacles, the community examples in this report illustrate that mechanisms currently exist that can help reduce fragmentation and inefficiencies, contain costs, and increase quality of care in ways that are responsive to people’s needs and preferences. Following is a summary of some of these mechanisms:
  - Care management or coordination, preferably involving interdisciplinary teams of experts as well as the consumer, is a way to ensure that the patient or client is considered holistically (i.e., all needs are assessed and addressed, not just those requiring immediate disease management). When problems are caught and addressed early, decline in physical or mental health and more frequent use of costly health care services may be avoided later.

- CD care responds to people’s innate desire for personal control, autonomy, and choice. It allows the consumer’s needs and preferences to dictate where and when services are to be delivered. Studies show that CD care leads to better satisfaction and fewer unmet needs than do traditional care models.
- When “money follows the person,” financing of health care and social services moves with the person to the most appropriate and preferred setting. Instead of fitting the person into predetermined service slots, because the financing system requires it, “money follows the person” is a consumer-focused approach, allowing the consumer’s needs and preferences to dictate the care plan and where and by whom services will be delivered.
- Integrating the delivery of acute and long-term care services financed by Medicare and Medicaid, using waivers for example, can reduce costly fragmentation and duplication of services and, instead, provide high-quality, flexible, consumer-centered, comprehensive, and continuous care across settings and providers.
- Supportive service programs that are linked to housing involve residents in determining what services should be provided, do not exclude recipients on the basis of functional or economic status, and provide services efficiently because they are delivered where people live.

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

- The 2000 N.O.D./Harris Survey of Community Participation showed that people with disabilities feel more isolated from their communities and participate in fewer activities than do people without disabilities. According to survey findings, community organizations should actively reach out to people with disabilities to encourage and expand their participation in community activities. All sectors need to be involved to achieve this objective, including the public, private, and nonprofit sectors.
- Drawing people with disabilities into community life does not mean creating “separate but equal” activities, but rather ensuring that people with disabilities can avail themselves of all of the opportunities 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 community examples in this report illustrate, where there is political will, there are many possible, creative ways to surmount the obstacles that prevent communities from being more livable for everyone.

## **Strategic Plan 2000: Making San Mateo County Livable for Older Adults and Adults with Disabilities**

*The needs of seniors and adults with disabilities are the foundation upon which this plan is constructed. While integrating the needs of these two groups into one strategic plan is somewhat unusual, there are many similarities that support addressing them in a single, comprehensive, and coordinated delivery system. Both seniors and adults with disabilities face comparable challenges and often need the same services and supports to assist them in maintaining their quality of life and maximizing their independence. Additionally, they share many of the same social stigma and negative stereotyping. We believe that, ideally, the best place for seniors and adults with disabilities to live is in the community, and that it is our responsibility to build upon the strengths of individuals and to reduce the barriers that impede their ability to live there comfortably and safely.*

—County of San Mateo, Strategic Plan for Services for Older Adults and Adults with Disabilities, FY 2000–FY 2005

### **Introduction**

As we indicated earlier in this report, we have not identified one single community that has accomplished all there is to do in each of the six areas included in the Livable Communities for Adults with Disabilities framework. Some communities, however, have made extraordinary progress in becoming more livable for people with disabilities and seniors. One such community is San Mateo County.

Like counties across the United States, San Mateo is facing a time of financial constraints. Providers and CBOs that serve seniors and adults with disabilities especially are feeling the crunch. Over the last few years, San Mateo has seen the consolidation of agencies, termination of long-standing CBOs, and dramatic decreases in the size of several organizations in their service network. Even the county, which receives funding from the state and Federal Government, has had to aggressively seek out new sources of revenue to support programs that are not mandated but are deemed important. A prime example is the need to raise funds on an ongoing basis to support San Mateo's Supplemental Meals on Wheels Program, which delivers meals to people,

such as younger people with disabilities, who do not qualify for the Older Americans Act-funded Meals on Wheels Program.

While San Mateo's Aging and Adult Services Division predicts increasing demand for services, the near-future funding climate does not seem bright. Three things set San Mateo apart from other communities and increase their chance of success: (1) a long history of collaboration, (2) a Strategic Plan for Services to Older Adults and Adults with Disabilities, and (3) the enviable ability to mobilize political will to prioritize the provision of appropriate services and the goal to improve quality of life for vulnerable populations, even in hard times.

Following is a description of how San Mateo developed their strategic plan, how the Aging and Adult Services Division is organized, and what it has accomplished in each of the six areas of the Livable Communities for Adults with Disabilities framework. Their achievements in some areas are stronger than in others—as is the case in most communities. Because it has articulated its vision and broken it down into small, concrete, actionable steps in its comprehensive strategic plan, San Mateo County is more likely than others to achieve its objectives in the long run.

## **Background**

San Mateo County, California, is situated on a 30-mile-long peninsula south of the city and county of San Francisco. The county's 450-square-mile area is 26 percent urban and 74 percent rural. Some of those rural areas are geographically isolated and sparsely populated.

According to Census 2000, the total population of San Mateo County is 707,161. Twelve and a half percent, or 88,085 people, are 65 years old and older. Among those 21 to 64 years of age, 16 percent (68,045) have a disability, and among those age 65 and over, 36 percent (30,397) have a disability. Although the majority (59.5%) of residents describe themselves as white, San Mateo has a significant minority population. Latinos (22%) and Asians (20%) account for 42 percent of the population, while there is a relatively small population of African Americans (3.5%).<sup>253</sup>

San Mateo County is considered affluent. The median household income is \$70,819, but calculations of average income are skewed by the county's proximity to the Silicon Valley,

where incomes are much higher. Despite the affluence that exists for many, there are still individuals—especially minorities, seniors, and adults with disabilities—who are living in poverty conditions.<sup>254</sup>

San Mateo is perceived as being a service-rich county because it has a broad, coordinated continuum of services for residents. Its Aging and Adult Services Division, located within the County's Health Services Agency, houses a variety of programs for adults 18 years of age and older and also serves as the county's Area Agency on Agency. The following organizations and programs are part of the Aging and Adult Services Division:

- Commission on Aging
- Commission on Disabilities
- Centralized Intake/TIES Line (toll-free information and assistance)
- Multidisciplinary 24-hour Response Team
- In-Home Supportive Services/Public Authority
- Adult Protective Services
- Public Guardian/Conservator
- Representative Payee
- Case Management Programs (AIDS, AIDS Waiver, Multipurpose Senior Services Program, Linkages)

The Division's 24-hour telephone line (1-800-675-8437) and Centralized Intake Unit serve as the single point of entry for adults into the system of publicly provided services. This single point of entry makes the county's adult services system more accessible, promotes comprehensive assessments of older adults, and strengthens the coordination of care among programs. The Centralized Intake Unit has a multidisciplinary team of professionals with expertise in public health, mental health, adult protective services, issues resulting from drug and alcohol misuse, and other related services, as well as intake, assessment, and short-term case planning. In addition to its in-house programs, the Division contracts with CBOs that work in partnership with the county to provide a coordinated system of care for seniors and adults with disabilities.

The Aging and Adult Services Division has three formal advisory bodies—the Commission on Aging, Commission on Disabilities, and In-Home Supportive Services Advisory Committee—that advise the Division on issues related to their constituents and provide opportunities for consumers and advocates to get involved in the development of public policy.

### **The Process of Developing a Strategic Plan**

In July 1992, the Aging and Adult Services Division convened a broad-based group of people with disabilities, seniors, caregivers, and service providers to form the New Beginning Coalition. The mission of the New Beginning Coalition was to improve the quality of life of San Mateo County's diverse population of older persons and adults with disabilities. The Coalition set out to meet this goal through the development of a long-range plan for a continuum of services that would be responsive to the needs of consumers, and acknowledge and incorporate the diversity that exists in San Mateo County. The Coalition envisioned an ideal service delivery system that would be integrated, flexible, and consumer-driven, without artificial constraints posed by funding sources.

A lengthy planning process involving more than 500 individuals ensued, and in 1995 the resulting Strategic Plan for Services to Older Adults and Adults with Disabilities was officially adopted by the San Mateo County Board of Supervisors, the Commission on Aging, the Commission on Disabilities, and community organizations throughout San Mateo County. Following the adoption of the Strategic Plan, an Implementation Coordination Committee (ICC) was established to serve as a central clearinghouse on Strategic Plan Implementation activities. The ICC meets monthly to review progress in the implementation of the Strategic Plan. To keep the community informed about how the Plan is being implemented, the ICC produces a quarterly newsletter, which is widely distributed.

In June 1999, the New Beginning Coalition, in collaboration with the San Mateo County Commission on Aging and Commission on Disabilities, began the development of an updated Strategic Plan. Organizations throughout San Mateo County were invited to submit copies of needs assessments, reports, and studies that affect seniors and adults with disabilities in San Mateo County. This information, along with resource materials from the Department of Finance



and various other organizations, was presented at the New Beginning Coalition's Baseline Conference in October 1999. The baseline material formed the foundation on which the new plan was constructed. It included projections of the senior population, number of adults with disabilities, and information on key indicators, such as poverty, housing, and health issues.

From October 1999 through January 2000, representatives from the New Beginning Coalition, Commission on Aging, Commission on Disabilities, and Aging and Adult Services, facilitated a series of 31 community forums to solicit input from consumers. Community forums targeted a broad range of seniors and adults with disabilities and, whenever necessary, were conducted in languages other than English.

On January 25, 2000, a group of 80 providers and consumers participated in a Strategic Planning Conference and reviewed the input from the forums and the recommended strategies for addressing the issues raised, which included health, transportation, affordable/accessible housing, emergency preparedness, elder and dependent adult abuse, access to information, and services and supports.

In the months following the Strategic Planning Conference, representatives from the New Beginning Coalition, Commission on Aging, and Commission on Disabilities and Aging and Adult Services reviewed the recommendations from the conference participants and developed the goals and objectives of Strategic Plan 2000. The work plans developed by the Commission on Aging and Commission on Disabilities at their respective annual retreats also became part of the Strategic Plan. Individual providers in the aging and disabilities network were asked for input as well, and any activities that corresponded to the Strategic Plan goals also were included in the Plan, making it a countywide plan for meeting the needs of seniors and adults with disabilities.

In October 2004, the Division held a Strategic Planning Conference, this time with input from 40 community forums, to decide on an action plan for 2005.

## **Strategic Plan 2000: Goals, Objectives, and Progress**

Strategic Plan 2000 is a detailed document that specifies seven goals, each with its own objectives, specific actions that need to be taken to achieve the objectives, and a timeframe in which to accomplish the objectives, ranging from one to five years. The seven broad goals of the Strategic Plan are as follows:

- Goal 1: To involve seniors and adults with disabilities in all aspects of the advocacy, planning, delivery, and evaluation of programs which serve them.
- Goal 2: To provide a coordinated network of services and supports that responds to local community needs.
- Goal 3: To maximize the independence of seniors and adults with disabilities by promoting affordable/accessible housing and transportation in safe environments and ensuring physical and programmatic access to community-based services and supports.
- Goal 4: To provide information, education, training, and consultation that enable individuals and organizations to understand issues facing seniors and adults with disabilities, be informed about resources, and connect with services and supports.
- Goal 5: To ensure that the network of services and supports for seniors and adults with disabilities reflects an understanding of and respect for the county's cultural and racial diversity and is free of ethnic, cultural, sexual orientation, and/or language barriers to use of services.
- Goal 6: To promote wellness and improve access to a variety of prevention and intervention services.
- Goal 7: To improve the security and well-being of seniors and adults with disabilities by responding to and reducing the incidence of violence, abuse, and neglect in San Mateo County.

Within these broad goals are numerous specific objectives, many of which correspond to the six areas included in this report's Livable Communities for Adults with Disabilities Framework. The San Mateo County Aging and Adult Services Division, on its own or through partnerships with

other government agencies or providers, has made progress in addressing each of these areas to make the county more livable for older people and adults with disabilities. Here is a sampling:

**Provide affordable, appropriate, accessible housing**

The Commission on Aging/Commission on Disabilities Joint Housing Task Force has produced brochures on universal design recommendations and residential visitability. Members have worked with county and city planning departments in an effort to promote those concepts, and these departments refer developers to the task force for review of proposed property development plans. The task force currently is developing a consumer resource guide on affordable/accessible housing.

**Ensure accessible, affordable, reliable, safe transportation**

San Mateo County Aging and Adult Services and SamTrans (the county's transit system) entered into a working partnership to develop a 10-year plan for accessible transportation—the Strategic Plan for Accessible Transportation Services (SPATS). The goal of the project was to identify the needs of individuals not currently served or underserved by the county's transportation system and create a plan for a comprehensive, accessible transportation system that responds to the needs of San Mateo County's seniors and adults with disabilities.

Members of the Commission on Aging, Commission on Disabilities, and New Beginning Coalition worked on the development of the plan and are now involved in its implementation. The groups are working with SamTrans on a comprehensive community education program that will help individuals who are not familiar with public transportation—especially those who have lost or are about to lose their driver's licenses—overcome barriers that prevent them from using the system.

**Adjust the physical environment for inclusiveness and accessibility**

The Commission on Disabilities' ADA Committee has been involved actively in the review of all county facilities for accessibility and the development and implementation of the county's ADA Transition Plan/Policies and Procedures.

All Aging and Adult Services, Commission on Aging, and Commission on Disabilities meetings are held at accessible locations, and assistive listening devices are available for those with hearing impairments.

### **Provide work, volunteer, and education opportunities**

The Division tries to set an example for other agencies by hiring people with disabilities who not only bring a wealth of professional experience to the job, but also provide a valuable and personal perspective to the Division's work. At the moment, two employees in the Division are people with disabilities.

In addition, the Division ensures that people with disabilities and seniors are represented in its various committees and commissions. For example, more than half of the commissioners serving on the Commission on Aging are older people, and the consumers serving on the Commission on Disabilities either have a disability or a family member with a disability.

### **Ensure access to key health and support services**

The Division's Supplemental Meals on Wheels program expands the availability of home-delivered meals to adults under 60 who are unable to prepare meals for themselves and have no one who can prepare the meals for them. The program was initiated by the Area Agency on Aging (before it became part of the Aging and Adult Services Division) to respond to the needs of nonseniors with functional disabilities whose independence was jeopardized without this type of support. Currently, the program is supported by a combination of donations by program participants, grants, and other fundraising efforts.

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

Each year, the San Mateo County Board of Supervisors and Commission on Disabilities cosponsor the "People Who Care Awards Dinner," which celebrates the contributions of agencies and individuals who have improved the lives of people with disabilities residing in San Mateo County.

In 2003, the event inaugurated the Art Showcase, which highlighted the creative talents of San Mateo County's artists with disabilities. Showcase sponsors included the San Mateo County Board of Supervisors, Commission on Disabilities, the Arts Commission, and ARTshare of San Mateo County. The success of the Art Showcase has prompted sponsors to continue supporting this popular feature. In 2004, 325 people attended the Awards Dinner/Art Showcase, and it is fast becoming the social event of the season.

For more information, contact

Shea Muller

Planner

San Mateo County Aging and Adult Services

Division of Health Services Agencies

225 37th Avenue

San Mateo, CA 94403

Email: [smuller@co.sanmateo.ca.us](mailto:smuller@co.sanmateo.ca.us)



## **Epilogue: Vision of a Livable Community**

John Smith is 67 years old; he is married and has two children and five grandchildren. Mr. Smith relies on a wheelchair to get around his home and his community and has lived in Model City his entire life.

About five years ago, Mr. and Mrs. Smith moved to the second floor of an apartment building. Their spacious apartment, built with universal design features, has a nice view of the tree-lined street. The Smiths consider their housing expenses affordable, as these costs, including utilities, account for less than 30 percent of their income. Their apartment building is one of several buildings designed and constructed by Property Owners Inc. (POI). POI was motivated to develop affordable, accessible housing by the Low-Income Housing Tax Credit (LIHTC) created by the Tax Reform Act of 1986. Under the LIHTC, property owners who allocate a specified portion of housing units to low-income households receive a federal tax credit that enables them to offset taxes on other income.<sup>255</sup>

Mr. Smith uses public transportation to get around town. His commute to work is only 20 minutes by bus. There is a bus stop on the corner of his apartment building and one block away from the Medical Center where he works as a part-time billing clerk. City buses run 24 hours daily and there is a bus stop about every two blocks. Recently, the city expanded the distance between the pole at the bus stop and the benches where people sit waiting so that wheelchairs can easily fit through. In the past, Mr. Smith had to maneuver off of the sidewalk into the busy street. Now he just rolls right through and feels much safer. Each bus fits two wheelchairs, and has an automated audible system to announce upcoming bus stops for passengers with visual impairments. The bus stops have Braille signs as well. Occasionally, Mr. Smith takes a taxi to get where he needs to go. The Taxi Commission is very proud of its Accessible Taxicab Program with accessible cabs and mandatory disability awareness training for new drivers.

Most everything that Mr. Smith needs is easy to get to. With curb cuts in all of the sidewalks, Mr. Smith can easily roll himself to the neighborhood stores and take care of his needs at the supermarket, bank, dry cleaners, pharmacy, and more. About once a month, Mr. and Mrs. Smith go out to eat with friends. Nearly all of the restaurants in Model City have Braille embossed

menus and accommodate diners with special dietary needs. The city's commitment to inclusiveness is further evident in its policy toward local businesses. Businesses without accessible entrances are fined \$100 a day until the entrances are modified. The city has a similar program in which private citizens are trained to write traffic tickets to people who abuse disabled parking spaces. The funds collected from both of these programs are directed toward integrated programs for people with and without disabilities. For example, the Commission for People with Disabilities' Cultural Committee uses a portion of these funds to plan outings for teenagers with and without disabilities to sports events, zoos, movies, and theme parks.

Mr. Smith is an avid sports fan and especially likes going to baseball games. Model City's baseball stadium is equipped with wheelchair seating and accessible restrooms and water fountains. During the summer, Mr. Smith goes swimming with his grandchildren in the city pool. The pool is equipped with access lifts and ramps for Mr. Smith's wheelchair. And right next door is an accessible adventure playground for children.

With five grandchildren, Mr. Smith is committed to education. As a member of the Public School Educational Committee, he makes arrangements for small groups of people with disabilities to share their personal experiences with third graders. The Commission for People with Disabilities supports several other education programs. The Commission's Vocational Committee provides transition services for high school students with disabilities that include job training and placement at local businesses. Long-term on-the-job monitoring and job coaching also are provided.

About a year ago, Mr. Smith was selected to serve as a juror on a civil case. His wheelchair easily fit through the court's entrance and the jury room. A sign language interpreter was present during the trial because the attorney for the plaintiff had a hearing impairment. In fact, the courthouse is fully accessible to people with disabilities, as are the city's other municipal buildings, including city hall and the police and fire stations. Polling sites for voting are accessible with electronic voting systems and one-on-one assistance available.

Recently, Model City's mayor implemented a citywide information and referral service, whereby citizens who dial 311 on their telephones reach live operators 24 hours a day. Residents can



obtain information about government agencies, employment, volunteer opportunities, education, transportation, housing, recreation, health care, support groups, and disability-specific organizations. The same information is available electronically on the City's user-friendly Web site, and will be printed annually. The Mayor's Disability Council holds monthly forums to discuss challenges and identify successful practices among local businesses. The latest success celebrated was the Visual Smoke Detector Giveaway Program for people with hearing impairments. Recipients were identified through the city's voluntary database of contact information for people with disabilities in case of a disaster.

Mr. Smith is an active member of his community. He works at the Medical Center, volunteers with the public school system, uses community resources, and participates in cultural activities and outdoor adventures. Mr. Smith feels very fortunate to live in Model City, USA.

Model City is based on applications from the N.O.D.'s Accessible America contest, and *Rolling*, a film by Gretchen Berland and Mike Majoros.



# Resources

## Chapter 1: Elements of Livable Communities for Adults with Disabilities

- American Association of Retired People (AARP), <http://www.aarp.org>
- Access-A-Ride, <http://www.mta.nyc.ny.us/nyct/paratran/guide.htm>
- AdvantAge Initiative, <http://www.advantageinitiative.org>
- American Institute of Architects, <http://www.aia.org>
- Lincoln Square Neighborhood Center (LSNC), Naturally Occurring Retirement Community-Supportive Services Program, (212) 874-0864, extension 119
- National Organization on Disability (N.O.D.), <http://www.nod.org>
- The Veterans Administration (VA) NY Harbor Healthcare System of the VA NY/NJ Veterans Healthcare Network, <http://www1.va.gov/visns/visn03/nyinfo.asp>
  - Visual Impairment Service Team Program (VIST), <http://www1.va.gov/visns/visn03/vistnyhhs.asp>
  - Home-Based Primary Care Program (HBPC), <http://www1.va.gov/visns/visn03/hbpc.asp>

## Chapter 2: Provide Affordable, Appropriate, Accessible Housing

- Alpha One, <http://www.alpha-one.org>
- City of Alexandria, Virginia Real Estate Tax Relief Program for Elderly and Disabled Persons, [http://alexandriava.gov/finance/rea\\_tax\\_relief.html](http://alexandriava.gov/finance/rea_tax_relief.html)
- Concrete Change, <http://www.concretechange.org>
- Consortium for Citizens with Disabilities, <http://www.c-c-d.org>
- Georgia's EasyLiving Home<sup>CM</sup> Program, <http://www.easylivinghome.org> and [http://www.concretechange.org/ga\\_easy\\_living.htm](http://www.concretechange.org/ga_easy_living.htm)

- Kim Wallace Adaptive Equipment Loan Program,  
<http://www.famemaine.com/ada/html/business/kimwallace-biz.htm>
- S.M.A.R.T.<sup>TM</sup> Housing Policy Initiative, <http://www.ci.austin.tx.us/ahfc/smart.htm>
- Technical Assistance Collaborative (TAC), <http://www.tacinc.org/index>
- Texas Home of Your Own (HOYO) Coalition, <http://www.onr.com/user/texashoyo> and  
<http://www.cms.hhs.gov/promisingpractices/txhoya.pdf>
- The Arc of Arkansas, <http://www.arcark.org>
- Universal Design: Homes for the Future Today,  
[http://www.cityofirvine.org/depts/cd/buildingsafety/accessibility\\_universal\\_design.asp](http://www.cityofirvine.org/depts/cd/buildingsafety/accessibility_universal_design.asp)
- U.S. Department of Housing and Urban Development (HUD), <http://www.hud.gov>

### **Chapter 3: Ensure Accessible, Affordable, Reliable, Safe Transportation**

- Allegan County Transportation, <http://www.mdot.state.mi.us/ptd/providers/allegan.cfm>
- Americans with Disabilities Act (ADA), <http://www.ada.gov>
- Charlotte Area Transit Service,  
<http://www.charmeck.org/Departments/CATS/About+Us/home.htm>
- Disability Advocates of Kent County, <http://www.disabilityadvocates.us>
- Faith in Motion, <http://www.graceoffice.org/fim.html>
- Federal Transit Administration (FTA), <http://www.fta.dot.gov>
- Florida Coordinated Community Transportation Program, <http://www.dot.state.fl.us/ctd>
- JAUNT, Inc., <http://www.ridejaunt.org>
- Job Access/Guaranteed Ride Home Program, <http://www.outreach1.org/jbxs>
- Job Access and Reverse Commute Program,  
[http://www.fta.dot.gov/grant\\_programs/specific\\_grant\\_programs/4339\\_ENG\\_HTML.htm](http://www.fta.dot.gov/grant_programs/specific_grant_programs/4339_ENG_HTML.htm)
- Metrolina Association for the Blind, <http://www.mab-jlbm.com>
- Rhode Island Public Transit Authority (RIPTA), <http://www.ripta.com>

- Sendero Group, <http://www.gps-talk.com>
- Transportation Options (TOPS), <http://www.broward.org/tpi02700.htm>
- United Spinal Association, <http://www.unitedspinal.org>

#### **Chapter 4: Adjust the Physical Environment for Inclusiveness and Accessibility**

- AccessAbility Decal Program,  
<http://bloomington.in.gov/egov/apps/services/index.pl?path=details&id=903&action=i&fDD=1-303>
- Americans with Disabilities Act (ADA), [www.ada.gov](http://www.ada.gov)
- Alpha One, <http://www.alpha-one.org>
- American Public Works Association, <http://www.apwa.net>
- Cambridge Commission for Persons with Disabilities,  
<http://www.ci.cambridge.ma.us/~DHSP/resources/disabil.html>
- Comprehensive Sidewalk Program, Nashville, Tennessee,  
<http://pw.nashville.gov/WEBPROD/SidewalkMain.asp>
- Façade Improvement Program, Cambridge, Massachusetts,  
<http://www.cambridgema.gov/~CDD/econdev/capital/fip.html>
- Greater Portland Landmarks Web Site, <http://www.portlandlandmarks.org>
- Project Civic Access, <http://www.usdoj.gov/crt/ada/civicac.htm>
- The Access Board, <http://www.access-board.gov>
- U.S. Department of Justice, <http://www.usdoj.gov>

#### **Chapter 5: Provide Work, Volunteer, and Education Opportunities**

- AbilityLinks.org, <http://www.abilitylinks.org>
- Alpha One, <http://www.alpha-one.org>
- Career Alliance, Inc., <http://www.careeralliance.org>

- Chicago Businessland Leadership Network (CBLN), <http://www.cbln.com>
- Computer/Electronic Accommodations Program (CAP), <http://www.tricare.osd.mil/cap>
- Customized Works!, <http://www.careeralliance.org/cworks>
- National Disability Mentoring Day (NDMD), <http://www.dmd-aapd.org>
- Eastern Shore Business Leadership Network, <http://www.esbln.org>
- Equal Employment Opportunity Commission (EEOC), <http://www.eeoc.gov>
- Governor's QUEST Internship Program for Persons with Disabilities,  
[sserra@dbm.state.md.us](mailto:sserra@dbm.state.md.us)
- Internal Revenue Service (IRS), <http://www.irs.gov>
- Job Accommodation Network (JAN), Office of Disability Employment Policy (ODEP),  
U.S. Department of Labor, <http://www.jan.wvu.edu>
- John J. Heldrich Center for Workforce Development, Rutgers, The State University of  
New Jersey, <http://www.heldrich.rutgers.edu>
- Mayoral Task Force on Employment of People with Disabilities, Chicago, Illinois,  
<http://www.disabilityworks.org>
- National Organization on Disability (N.O.D.), <http://www.nod.org>
- New Freedom Initiative (NFI),  
<http://www.whitehouse.gov/news/freedominitiative/freedominitiative.html>
- One-Stop Career Centers, <http://www.dol.gov/dol/topic/training/onestop.htm>
- Rehabilitation Services Administration, U.S. Department of Education,  
<http://www.ed.gov/about/offices/list/osers/rsa>
- Social Security Administration (SSA), <http://www.ssa.gov>
- Ticket to Work (TTW) and Self-Sufficiency Program, <http://www.yourtickettowork.com>
- U.S. Business Leadership Network (USBLN), <http://www.usbln.com>
- U.S. Department of Labor Office of Disability Employment Policy,  
<http://www.dol.gov/odep>

- Uptown Bill's Small Mall, <http://www.uptownbills.org>

## **Chapter 6: Ensure Access to Key Health and Support Services**

- Centers for Medicare and Medicaid Services (CMS), <http://www.cms.hhs.gov>
- Healthy People 2010, <http://www.healthypeople.gov>
- Minnesota Disability Health Options (MnDHO),  
[http://www.dhs.state.mn.us/main/groups/healthcare/documents/pub/dhs\\_id\\_006272.hcsp](http://www.dhs.state.mn.us/main/groups/healthcare/documents/pub/dhs_id_006272.hcsp)
- National Cooperative Bank Development Corporation (NCBDC), <http://www.ncbdc.org>
- Office of the Assistant Secretary for Planning and Evaluation, <http://aspe.hhs.gov>
- Robert Wood Johnson Foundation (RWJF), <http://www.rwjf.org>
- Wisconsin Partnership Program, <http://www.dhfs.state.wi.us/WIpartnership>
- The Arc of Arkansas, <http://www.arcark.org>

## **Chapter 7: Encourage Participation in Civic, Cultural, Social, and Recreational Activities**

- Adaptive Recreation Services, City of Phoenix Parks and Recreation Department,  
<http://www.phoenix.gov/PRL/adrecsvc.html#RIVER>
- AXIS Dance Company, <http://www.axisdance.org>
- Daring Adventures, <http://www.phoenix.gov/PRL/dadv.html>
- Experiential Education Initiative (EEI), The John F. Kennedy Center for the Performing Arts, [access@kennedy-center.org](mailto:access@kennedy-center.org)
- Faith in Motion, <http://www.graceoffice.org/fim.html>
- FaithWays, <http://mn.nami.org/faithways.html>
- Harris County Clerk, Houston, Texas, <http://www.harrisvotes.org/index2.htm>
- National Alliance for the Mentally Ill (NAMI), <http://www.nami.org>
- National Organization on Disability (N.O.D.), <http://www.nod.org>

- River Rampage, <http://www.phoenix.gov/PRL/adreclvc.html#RIVER>
- Toastmasters International, <http://www.toastmasters.org>



# **Appendix: Mission of the National Council on Disability**

## **Overview and Purpose**

The National Council on Disability (NCD) is an independent federal agency with 15 members appointed by the President of the United States and confirmed by the U.S. Senate. The overall purpose of NCD is to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities, regardless of the nature or significance of the disability, and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society.

## **Specific Duties**

The current statutory mandate of NCD includes the following:

- Reviewing and evaluating, on a continuing basis, policies, programs, practices, and procedures concerning individuals with disabilities conducted or assisted by federal departments and agencies—including programs established or assisted under the Rehabilitation Act of 1973, as amended, or under the Developmental Disabilities Assistance and Bill of Rights Act, as well as all statutes and regulations pertaining to federal programs that assist such individuals with disabilities—to assess the effectiveness of such policies, programs, practices, procedures, statutes, and regulations in meeting the needs of individuals with disabilities.
- Reviewing and evaluating, on a continuing basis, new and emerging disability policy issues affecting individuals with disabilities at the federal, state, and local levels and in the private sector, including the need for and coordination of adult services, access to personal assistance services, school reform efforts and the impact of such efforts on individuals with disabilities, access to health care, and policies that act as disincentives for individuals to seek and retain employment.
- Making recommendations to the President, Congress, the Secretary of Education, the director of the National Institute on Disability and Rehabilitation Research, and other officials of federal agencies about ways to better promote equal opportunity, economic self-sufficiency, independent living, and inclusion and integration into all aspects of society for Americans with disabilities.
- Providing Congress, on a continuing basis, with advice, recommendations, legislative proposals, and any additional information that NCD or Congress deems appropriate.
- Gathering information about the implementation, effectiveness, and impact of the Americans with Disabilities Act of 1990 (ADA) (42 U.S.C. § 12101 et seq.).
- Advising the President, Congress, the commissioner of the Rehabilitation Services Administration, the assistant secretary for Special Education and Rehabilitative Services within the Department of Education, and the director of the National Institute on Disability and Rehabilitation Research on the development of the programs to be carried out under the Rehabilitation Act of 1973, as amended.

- Providing advice to the commissioner of the Rehabilitation Services Administration with respect to the policies and conduct of the administration.
- Making recommendations to the director of the National Institute on Disability and Rehabilitation Research on ways to improve research, service, administration, and the collection, dissemination, and implementation of research findings affecting people with disabilities.
- Providing advice regarding priorities for the activities of the Interagency Disability Coordinating Council and reviewing the recommendations of this council for legislative and administrative changes to ensure that such recommendations are consistent with NCD's purpose of promoting the full integration, independence, and productivity of individuals with disabilities.
- Preparing and submitting to the President and Congress an annual report titled *National Disability Policy: A Progress Report*.

## **International**

In 1995, NCD was designated by the Department of State to be the U.S. Government's official contact point for disability issues. Specifically, NCD interacts with the special rapporteur of the U.N. Commission for Social Development on disability matters.

## **Consumers Served and Current Activities**

Although many government agencies deal with issues and programs affecting people with disabilities, NCD is the only federal agency charged with addressing, analyzing, and making recommendations on issues of public policy that affect people with disabilities, regardless of age, disability type, perceived employment potential, economic need, specific functional ability, veteran status, or other individual circumstance. NCD recognizes its unique opportunity to facilitate independent living, community integration, and employment opportunities for people with disabilities by ensuring an informed and coordinated approach to addressing the concerns of people with disabilities and eliminating barriers to their active participation in community and family life.

NCD plays a major role in developing disability policy in America. In fact, NCD originally proposed what eventually became ADA. NCD's present list of key issues includes improving personal assistance services, promoting health care reform, including students with disabilities in high-quality programs in typical neighborhood schools, promoting equal employment and community housing opportunities, monitoring the implementation of ADA, improving assistive technology, and ensuring that people with disabilities who are members of diverse cultures fully participate in society.

## **Statutory History**

NCD was established in 1978 as an advisory board within the Department of Education (P.L. 95-602). The Rehabilitation Act Amendments of 1984 (P.L. 98-221) transformed NCD into an independent agency.



## Endnotes

<sup>1</sup> White House Domestic Policy Council. (2004, March). *The President's New Freedom Initiative for People with Disabilities: The 2004 Progress Report, Executive Summary*. Washington, DC: White House Domestic Policy Council. Retrieved on September 20, 2004, from <http://www.whitehouse.gov/infocus/newfreedom/toc-2004.html>.

<sup>2</sup> AdvantAge Initiative Web site at [www.advantageinitiative.org](http://www.advantageinitiative.org).

<sup>3</sup> 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](http://www.c-c-d.org/going_alone.pdf).

<sup>4</sup> 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>.

<sup>5</sup> O'Hara & Miller, 2000.

<sup>6</sup> 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](http://www.bts.gov/publications/freedom_to_travel).

<sup>7</sup> National Organization on Disability (N.O.D.). (2004a). "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/pdffiles/harris2004/harris2004\\_summ.pdf](http://www.nod.org/pdffiles/harris2004/harris2004_summ.pdf). More information on this survey is available at: <http://www.nod.org/content.cfm?id=1537>.

<sup>8</sup> 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>.

<sup>9</sup> Harris Interactive, Inc. (2000a). *2000 N.O.D./Harris Survey of Community Participation*. New York: Harris Interactive, Inc.

<sup>10</sup> Waldrop, J., & Stern, S.M. (2003, March). *Disability Status: 2000. Census 2000 Brief*. Washington, DC: U.S. Census Bureau. Retrieved from <http://www.census.gov/prod/2003pubs/c2kbr-17.pdf>.

<sup>11</sup> Manton, K.G., Corder, L., & Stallard, E. (1997). Chronic disability trends in elderly United States populations: 1982–1994. *Proceedings of the National Academy of Sciences*, 94(6):2593–2598; Manton, K.G., & Gu, X. (2001). Changes in the prevalence of chronic disability in the

United States black and nonblack population above age 65 from 1992 to 1999. *Proceedings of the National Academy of Sciences*, 98 (11), 6354–6359.

<sup>12</sup> Gibson, M.J., Freiman, M., Gregory, S., Kassner, E., Kochera, A., Mullen, F., Pandya, S., Redfoot, D., Straight, A., & Wright, B. (2003). *Beyond 50 2003: A Report to the Nation on Independent Living and Disability*. Washington, DC: AARP, p. 40.

<sup>13</sup> Waldrop & Stern, 2003.

<sup>14</sup> Ibid.

<sup>15</sup> Ibid.

<sup>16</sup> Gibson et al., 2003, p. 137.

<sup>17</sup> *AARP/Harris Interactive Survey of Persons 50 and Older with Disabilities*. (2002, September).

<sup>18</sup> Gibson et al., 2003, p. 152.

<sup>19</sup> Ibid.

<sup>20</sup> Ibid, p. 141.

<sup>21</sup> Ibid, p. 153.

<sup>22</sup> White House Domestic Policy Council, 2004.

<sup>23</sup> Feldman, P.H., Oberlink, M.R., Simantov, E., & Gursen, M.D. (2004). “A Tale of Two Older Americas: Community Opportunities and Challenges.” AdvantAge Initiative 2003 National Survey of Adults Aged 65 and Older. New York, NY: Center for Home Care Policy and Research, Visiting Nurse Service of New York. Retrieved at [http://www.vnsny.org/advantage/AI\\_NationalSurveyReport.pdf](http://www.vnsny.org/advantage/AI_NationalSurveyReport.pdf).

<sup>24</sup> Gibson et al., 2003, p. 177.

<sup>25</sup> Ibid, p. 145.

<sup>26</sup> The Veterans Administration (VA) NY Harbor Healthcare System of the VA NY/NJ Veterans Healthcare Network. For more information, see the VA Web site at <http://www1.va.gov/visns/visn03/nyinfo.asp>.

<sup>27</sup> Gibson et al., 2003, pp. 120–55.

<sup>28</sup> For more information, see [http://www.aia.org/liv\\_principles](http://www.aia.org/liv_principles).

<sup>29</sup> The AdvantAge Initiative Elder-Friendly Community Framework was developed on the basis of background research and 14 separate focus groups conducted with people in three age

groups—older-old (ages 75+), younger-old (ages 60–74), and younger ages (ages 35–59)—as well as community leaders in four different cities around the country: Allentown, PA; Asheville, NC; Chicago, IL; and Long Beach, CA. Focus group participants were asked to critique their communities and provide opinions about the elements of an ideal, “elder-friendly” community that addresses the needs and aspirations of well elders, as well as elders with disabilities or at risk of developing disabilities. The background research and focus group results were synthesized into a framework having four “domains” with three or four specific “dimensions” in each.

<sup>30</sup> For more information about Alpha One, see <http://www.alpha-one.org>.

<sup>31</sup> The Kim Wallace Adaptive Equipment Loan Program is a program of the Finance Authority of Maine (FAME), an independent state agency that develops and administers programs that help people and businesses achieve success by providing access to capital. For more information, see <http://www.famemaine.com>.

<sup>32</sup> O’Hara & Miller, 2000.

<sup>33</sup> The Arc & UCP Public Policy Collaboration, 2004.

<sup>34</sup> For example, renters who pay 50 percent or more of their income on housing or who live in severely substandard or inadequate housing.

<sup>35</sup> O’Hara & Miller, 2000, p. 7.

<sup>36</sup> O’Hara, A., & Miller, E. (2001). *Priced Out in 2000*. Boston, MA: Technical Assistance Collaborative, Inc & Washington, DC: Consortium for Citizens with Disabilities Housing Task Force, p. 6. Retrieved at <http://www.tacinc.org>.

<sup>37</sup> Commission on Affordable Housing and Health Facility Needs for Seniors in the 21st Century. (2002, June 30). *A Quiet Crisis in America: A Report to Congress by the Commission on Affordable Housing and Health Facility Needs for Seniors in the 21st Century*. Washington, DC: Commission on Affordable Housing and Health Facility Needs for Seniors in the 21st Century, p.5. Retrieved on at [http://www.seniorscommission.gov/pages/final\\_report/index.html](http://www.seniorscommission.gov/pages/final_report/index.html).

<sup>38</sup> U.S. Department of Housing and Urban Development. (1999). *Housing our Elders*, Washington, DC: U.S. Department of Housing and Urban Development, Office of Policy Development and Research, p. 37. Retrieved at <http://www.huduser.org/publications/hsgspec/housec.html>.

<sup>39</sup> O’Hara & Miller, 2000, p. 6.

<sup>40</sup> Project Access is a pilot program of the U.S. Department of Housing and Urban Development.

<sup>41</sup> O’Hara & Miller, 2001, p. 3.

<sup>42</sup> O’Hara & Miller, 2000, p. 10.

<sup>43</sup> O'Hara & Miller, 2000, p. 13.

<sup>44</sup> Neighborhood Housing and Community Development, City of Austin. (2004, Spring). *S.M.A.R.T. Housing™ Policy Resource Guide* Austin, TX: Neighborhood Housing and Community Development, City of Austin. Retrieved at <http://www.ci.austin.tx.us/ahfc/downloads/smartguide.pdf>.

<sup>45</sup> Austin Housing Finance Corporation Web site at <http://www.ci.austin.tx.us/ahfc/smart.htm>.

<sup>46</sup> Personal correspondence, Stuart Hersh, S.M.A.R.T. Housing Coordinator, Neighborhood Housing and Community Development, City of Austin, September 27, 2004.

<sup>47</sup> Austin's Visitability Ordinance sets standards for single-family homes, duplexes, and triplexes. Austin also sets standards for accessibility in multifamily homes.

<sup>48</sup> Tillery, D. (2004). *Supportive Housing Initiative in Arkansas*. Paper prepared for Information Brokering for Long-Term Care, a project of the Center for Home Care Policy & Research, Visiting Nurse Service of New York; funded by The Robert Wood Johnson Foundation, p. 5.

<sup>49</sup> Funds were used from the Arkansas Development Finance Authority (ADFA) HOME program, the Federal Home Loan Bank, Historic Preservation Tax Credits, and a Landmark Grant from the Historic Preservation Trust (Tillery, 2004, p. 12).

<sup>50</sup> The Arc, Trinity Court, Web site at [http://www.arcarts.org/trinity\\_court.htm](http://www.arcarts.org/trinity_court.htm).

<sup>51</sup> Ibid.

<sup>52</sup> The Arc, Eastside Lofts, Web site at <http://www.arcarts.org/eastside%20lofts.htm>.

<sup>53</sup> Tillery, 2004.

<sup>54</sup> The Arc, Westside Lofts. Web site at [http://www.arcarts.org/westside\\_lofts.htm](http://www.arcarts.org/westside_lofts.htm).

<sup>55</sup> Personal communication with Cynthia Stone, Chief Operating Officer, The Arc of Arkansas, May 17, 2004.

<sup>56</sup> City of Alexandria, Virginia, Finance Department. (2004). *Real Estate Tax Relief Program for Elderly and Disabled Persons Tax Year 2004*. Retrieved on September 8, 2004, from [http://ci.alexandria.va.us/finance/rea\\_tax\\_relief.html](http://ci.alexandria.va.us/finance/rea_tax_relief.html).

<sup>57</sup> Personal correspondence, Gary Rossi, Revenue Collections Specialist, Revenue Division, Department of Finance, City of Alexandria, May 11, 2004.

<sup>58</sup> Gross household income includes the income of both spouses and any income above \$8,500 per year of other relatives living in the home.

<sup>59</sup> Personal correspondence, Gary Rossi, September 28, 2004.



<sup>60</sup> The National Home of Your Own Alliance (HOYO) grew from a locally based homeownership pilot program in New Hampshire. HOYO was established in 1993 as a five-year agreement between the Institute on Disability at the University of New Hampshire and the Administration on Developmental Disabilities. While funding for the national program has ended, the information, referral telephone number, and Web site are still valid and operational.

<sup>61</sup> Lenders may be state and local housing development and finance agencies, banks, savings and loans, credit unions, and mortgage companies.

<sup>62</sup> Disability organizations may be state and local government agencies; private service providers; and family, advocacy, and consumer groups.

<sup>63</sup> Personal Communication, Jean Langendorf, United Cerebral Palsy of Texas, May 2004.

<sup>64</sup> The coalition includes AARP Georgia, Atlanta Regional Commission, Concrete Change, Easter Seals–Southern Georgia, Fannie Mae Atlanta Partnership Office, Georgia Department of Community Affairs, Governor’s Council on Developmental Disabilities, Home Builders Association of Georgia, Shepherd Center, the Statewide Living Council of Georgia, and the Universal Design Alliance.

<sup>65</sup> Concrete Change. *Georgia EasyLiving Home<sup>CM</sup> Program*. Information available at [http://www.concretechange.org/ga\\_easy\\_living.htm](http://www.concretechange.org/ga_easy_living.htm).

<sup>66</sup> Personal communication, Bonnie Bonham, Program Director, EasyLiving Home<sup>CM</sup>, May 20, 2004.

<sup>67</sup> EasyLiving Home<sup>CM</sup> Web site at <http://www.easylivinghome.org>.

<sup>68</sup> Kochera, A. (2002). *Accessibility and Visitability Features in Single-Family Homes: A Review of State and Local Activity*. Washington, DC: AARP Public Policy Institute. Retrieved from [http://research.aarp.org/il/2002\\_03\\_homes.pdf](http://research.aarp.org/il/2002_03_homes.pdf).

<sup>69</sup> City of Irvine. (2000, December 14). *New Universal Design Program Makes New Homes in Irvine More Accessible and Livable for All Ages and Abilities* (Press Release #2000-48). Irvine, CA: City of Irvine.

<sup>70</sup> Kochera, 2002.

<sup>71</sup> City of Irvine, 2000.

<sup>72</sup> The Irvine Company is a 110-year-old, privately held real estate development company best known for the balanced, sustainable communities it has planned and developed on The Irvine Ranch® in Orange County, California. The Irvine Ranch is considered one of the largest and most successful master-planned urban environments in the United States. Approximately 240,000 people live on The Irvine Ranch. For more information, see <http://www.irvinecompany.com>.

<sup>73</sup> City of Irvine. (2002, July 9). *Request for City Council Action: Report on the Universal Design Program for New Homes*. Irvine, CA: City of Irvine.

<sup>74</sup> Participating builders include Beazer Homes, Brookfield Homes, California Pacific Homes, Centex Homes, Fieldstone Communities, Greystone Homes, John Laing Homes, K. Hovanian Homes, Lennar Homes of California, Richmond American Homes, Shea Homes, Standard Pacific of Orange County, Taylor Woodrow Homes, William Lyon Homes.

<sup>75</sup> City of Irvine, 2002.

<sup>76</sup> Ibid.

<sup>77</sup> Personal Communication, Eric Tolles, September 27, 2004.

<sup>78</sup> U.S. Department of Transportation, Bureau of Transportation Statistics, 2003. Retrieved on May 10, 2004, from [http://www.bts.gov/publications/freedom\\_to\\_travel/pdf/entire.pdf](http://www.bts.gov/publications/freedom_to_travel/pdf/entire.pdf).

<sup>79</sup> Ibid, p. 5.

<sup>80</sup> Ibid.

<sup>81</sup> Bureau of Transportation Statistics, U.S. Department of Transportation. (2003, April). "Transportation Difficulties Keep Over Half a Million Disabled at Home." *BTS Issue Brief*, 3. Retrieved on July 6, 2004, from [http://www.bts.gov/publications/issue\\_briefs/number\\_03](http://www.bts.gov/publications/issue_briefs/number_03).

<sup>82</sup> Translated literally, paratransit means "alongside transit." It refers to ADA-required complementary transit services that provide accessible transportation to people with mobility impairments who live in areas served by fixed-route public transit systems, but are not able to use the fixed-route service. 49 *Code of Federal Regulations* Parts 27, 37, and 38, "Transportation for Individuals With Disabilities; Final Rule," published in the *Federal Register*, September 6, 1991.

<sup>83</sup> The Access Board. *Manuals for ADA Accessibility Guidelines for Transportation Vehicles*. Retrieved on May 12, 2004, from <http://www.access-board.gov/transit/manuals/Manuals-list.htm>.

<sup>84</sup> If vehicles are remanufactured after August 25, 1990, to extend their useful life for 5 years or more in the case of buses and rapid and light rail vehicles, or for 10 years in the case of commuter and intercity rail cars, then the vehicles must be made accessible to the maximum extent feasible. Retrieved on May 10, 2004, from <http://www.access-board.gov/transit/manuals/Transit%20Manual%20-%20intor.htm>.

<sup>85</sup> Humm, A. (2004, May 5). "12,000 NYC Taxis; Five Are Accessible," *Gotham Gazette*. Retrieved on September 3, 2004, from [www.gothamgazette.com/article/civilrights/20040507/3/970](http://www.gothamgazette.com/article/civilrights/20040507/3/970); and Masburn, R. (2004, April 22) "Wheelchair Accessible London," *The New York Times*. Retrieved on September 3, 2004, from <http://www.nytimes.com/2004/04/18/travel/18wheelchair.html>.

<sup>86</sup> Dorn, J.L. (2002, June 20). “Testimony before the Subcommittee on Highways and Transit of the Committee on Transportation and Infrastructure.” U.S. House of Representatives. Retrieved on May 13, 2004, from <http://www.fta.dot.gov/library/intro/st/062002.html>.

<sup>87</sup> Easter Seals, Project ACTION. (2004, Spring). Leaders at Forum Gather to Proclaim: “United We Ride.” *Project ACTION Update (Accessible Transportation in our Nation)*. Retrieved on June 12, 2004, from [http://projectaction.easterseals.com/site/DocServer/spring\\_2004pdf.pdf?docID=5264](http://projectaction.easterseals.com/site/DocServer/spring_2004pdf.pdf?docID=5264).

<sup>88</sup> “Framework for Action Building The Fully Coordinated Transportation System.” Retrieved from <http://www.fta.dot.gov/CCAM/framework.html>.

<sup>89</sup> In this context, coordination means “pooling the transportation resources and activities of several human service agencies with one another and/or with mass transit operation.” For a full description of the programs and more examples see Burkhardt, J.E. (2000, September). *Coordinated Transportation Systems*. Washington, DC: The Public Policy Institute, AARP. Retrieved on May 12, 2004, from [http://research.aarp.org/consume/2000\\_16\\_transport.pdf](http://research.aarp.org/consume/2000_16_transport.pdf); and Federal Transit Administration (FTA). July 7, 2004. *Innovative State & Local Planning for Coordinated Transportation*. Retrieved on July 7, 2004, from [http://www.fta.dot.gov/907\\_ENG\\_HTML.htm](http://www.fta.dot.gov/907_ENG_HTML.htm).

<sup>90</sup> Bush, President George W. (2001, February). “Foreword” to the *New Freedom Initiative*. Retrieved on June 17, 2004, from <http://www.whitehouse.gov/news/freedominitiative/freedominitiative.html>.

<sup>91</sup> The White House. (2004, March). *New Freedom Initiative: A Progress Report*. Retrieved on June 17, 2004, from [www.whitehouse.gov/infocus/newfreedom/nfipprogress.pdf](http://www.whitehouse.gov/infocus/newfreedom/nfipprogress.pdf).

<sup>92</sup> Information on the services retrieved on May 19, 2004, from <http://www.dot.state.fl.us/ctd/>; also see Florida Association of Coordinated Transportation Systems Incorporated, “Ensuring the Mobility for Florida’s Transportation Disadvantaged.” Retrieved on May 19, 2004, from <http://www.flafacts.com>.

<sup>93</sup> “Transportation disadvantaged” means “persons who because of physical or mental disability, income status, or age are unable to transport themselves or to purchase transportation and are, therefore, dependent upon others to obtain access to health care, employment, education, shopping, social activities, or other life-sustaining activities, or children who are handicapped or high-risk or at-risk” (Florida Statutes, Chapter 427.011-s 411.202). Retrieved on May 19, 2004, from <http://www.broward.org/tpi02600.htm>.

<sup>94</sup> For information on the program, see Broward County Florida Transportation Planning Division, Paratransit/ADA. Retrieved on May 19, 2004, from <http://www.broward.org/tpi02700.htm>.

<sup>95</sup> For a detailed description of eligibility, see “Broward County Transit ADA Paratransit Service Eligibility Criteria Guidelines.” Retrieved on May 19, 2004, from <http://www.broward.org/bct/criteria.pdf>.

<sup>96</sup> JAUNT, Inc. Retrieved on September 5, 2003, from <http://www.ridejaunt.org>.

<sup>97</sup> Federal Transit Administration. *Innovative State & Local Planning for Coordinated Transportation*. Retrieved on June 7, 2004, from [http://www.fta.dot.gov/907\\_ENG\\_HTML.htm](http://www.fta.dot.gov/907_ENG_HTML.htm); also see Sweetwater Transit Authority Resources (STAR). Retrieved on June 7, 2004, from <http://www.nccic.org/ccpartnerships/profiles/star.htm>.

<sup>98</sup> For more information about Job Access and Reverse Commute (JARC) grants, contact Sue Masselink, Office of Program Management, Federal Transit Administration, Room 9315, 400 7th Street, SW., Washington, DC 20590; Phone: (202) 366-2053; TDD (800) 877-8339 (TDD/FIRS); Email: [sue.masselink@fta.dot.gov](mailto:sue.masselink@fta.dot.gov). Detailed information about efforts funded through JARC and other federal programs is also available in the funding guide, “Opportunities for Federal Funding and Promising Practices,” (2002, June). Easter Seals Project Action (ESPA) See the Building Mobility Partnerships for People with Disabilities Web site at <http://projectaction.easterseals.com>. (ESPA is funded by the FTA. Its mission is to encourage and facilitate cooperation between the disability and transportation communities with the goal of achieving universal access through transportation for people with disabilities nationwide. ESPA provides technical assistance to transit providers that are implementing ADA and oversees innovative demonstration projects in transportation for people with disabilities).

<sup>99</sup> JARC funding for Allegan County was \$150,000 in FY 1999 and \$150,000 in FY 2000.

<sup>100</sup> JARC Funding for the Guaranteed Ride Program (GRP) was \$499,000 for FY 1999, \$500,000 for FY 2000, \$498,900 for FY 2001, and \$500,000 for FY 2002.

<sup>101</sup> For more information, see [http://www.outreach1.org/p\\_home/paratran.htm](http://www.outreach1.org/p_home/paratran.htm).

<sup>102</sup> In FY 2000, the Rhode Island Public Transit Authority (RIPTA) applied \$100,000 of its total JARC funds to the Flex Service program. Overall JARC funding to RIPTA from the FTA was \$1,000,000 for FY 1999; \$500,000 for FY 2000; \$997,800 for FY 2001; and \$2,000,000 for FY 2002.

<sup>103</sup> Transportation Advocacy Project (Pittsburgh, PA). (2001, Winter). “Accessible Taxicabs Part 1: A Look at Accessible Taxi Service Across the Country.” *ACT (Advocate for Consumer Transportation) Newsletter*, pp. 7–10. Retrieved on June 16, 2004, from [http://www.ridesforallpa.com/Accessible%20Taxicabs%20\(11-16-00\).htm](http://www.ridesforallpa.com/Accessible%20Taxicabs%20(11-16-00).htm).

<sup>104</sup> Medallions essentially are a license sold by many cities and municipalities allowing an individual or company to operate a taxicab in certain area. One mechanism cities use to increase the number of accessible taxis is to increase the number of new “medallions,” or licenses, for sale. Medallions for accessible vehicles are priced below sedan medallions as a purchase incentive.

<sup>105</sup> “Millage” is a tax rate on property, expressed in mills per dollar of value of the property.

<sup>106</sup> U.S. Department of Justice Web site at <http://www.usdoj.gov>.

<sup>107</sup> U.S. Department of Justice Disability Rights Section at <http://www.usdoj.gov/crt/drs/drshome.htm>.

<sup>108</sup> For more information, see the Web site for Project Civic Access at <http://www.usdoj.gov/crt/ada/civicac.htm>.

<sup>109</sup> U.S. Department of Justice, Civil Rights Division, Disability Rights Section. “The ADA and City Governments: Common Problems.” Retrieved on October 6, 2004, from <http://www.usdoj.gov/crt/ada/comprob.htm>; see also U.S. Department of Justice, Civil Rights Division, Disability Rights Section. (2000, March). “Americans with Disabilities Act: ADA Guide for Small Towns, and ADA Stories—Four Communities Improve Civic Access.” Retrieved on October 6, 2004, from <http://ada.gov/smtown.htm>. These and other materials can be accessed at <http://ada.gov/publicat.htm>.

<sup>110</sup> See the Americans with Disabilities Act (ADA) Web site at <http://www.ada.gov> for more information.

<sup>111</sup> For more information, go to <http://www.cambridgema.gov/~CDD/econdev/capital/fip.html>.

<sup>112</sup> For example, Disabled Access Tax Credit (Title 26, Internal Revenue Code, Section 44).

<sup>113</sup> The Access Board is an independent federal agency that develops and maintains accessibility requirements for the built environment, provides technical assistance and training on these requirements, and enforces accessibility standards for federally funded facilities. For more information visit <http://www.access-board.gov>. In July, 2004, the Access Board released updated accessibility guidelines for facilities covered by ADA to coincide with the 14th anniversary of ADA’s enactment into law.

<sup>114</sup> Personal communication with Dennis Pratt, June 14, 2004.

<sup>115</sup> Kansas City has 5,900 “lane miles,” that is, the number of miles of roadway including all traffic lanes.

<sup>116</sup> RPM Transportation Consultants, LLP. (2003, March). *Final Report: Nashville-Davidson County Strategic Plan For Sidewalks & Bikeways*. Nashville, TN: The Metropolitan Government of Nashville and Davidson County, Tennessee. Retrieved from [http://www.nashville.gov/mpc/sidewalks/finalplan\\_march03.htm](http://www.nashville.gov/mpc/sidewalks/finalplan_march03.htm).

<sup>117</sup> The direct link is <http://pw.nashville.gov/WEBPROD/InteractiveMap.asp>.

<sup>118</sup> The public right-of-way is the term used to describe all publicly owned land that is used to ensure the ease of public and commercial transportation, including roads, sidewalks, bicycle paths, and freight passages. Public rights-of-way also accommodate elements that facilitate these

activities, including traffic signals, signs, streetlights, and, in some cases, public and private utilities. For more information, see Public Rights-of-Way Access Advisory Committee. (2001, January) "Building a True Community: Final Report Public Rights-of-Way Access Advisory Committee." Washington, DC: The Access Board. Retrieved from <http://www.access-board.gov/prowac/commrept>.

<sup>119</sup> Personal communication with Renee Johnson, June 24, 2004.

<sup>120</sup> Under Title I of the Rehabilitation Act of 1973, states receive federal grants to operate comprehensive vocational rehabilitation (VR) programs. The funds are awarded to designated VR agencies within each state. Eligibility for VR services requires that an individual have a physical or mental impairment, which constitutes or results in a substantial impediment to employment, and be able to benefit from VR services to achieve an employment outcome. A second criterion for eligibility is that individuals require VR services to prepare for, secure, retain, or regain employment. People who receive Supplemental Security Income (SSI) and/or Social Security Disability Insurance (SSDI) are presumed eligible for VR services unless there is clear evidence that they are too disabled to benefit. Priority is given to individuals with the most significant disabilities over those with less significant disabilities. VR agencies cover a wide variety of services such as vocational training, transportation, interpreters, school-to-work transition, personal assistance services, rehabilitation technology services, supported employment services, and job placement services. For more information, see the Web site of the U.S. Department of Education, Office of Special Education and Rehabilitative Services at <http://www.ed.gov/about/offices/list/osers/rsa/faq.html>.

<sup>121</sup> For more information about Ticket to Work (TTW), see page 85 in this chapter.

<sup>122</sup> To meet Social Security Administration confidentiality requirements, only first names are used in this introduction.

<sup>123</sup> Alpha One Enterprises. (2003, Fall). "Tickets (to job services) Are Coming," *One in Five*, 2(4):1, 4. Portland, ME. Retrieved from <http://www.alphaonenow.org>.

<sup>124</sup> SSA, Equal Employment Opportunity Commission (EEOC), & U.S. Department of Justice, Civil Rights Division. (2002, October). "Americans with Disabilities Act: A Guide for People with Disabilities Seeking Employment." Retrieved at <http://www.usdoj.gov/crt/ada/workta.pdf>.

<sup>125</sup> EEOC. (1997, January 15). "The ADA: Questions and Answers." Retrieved on July 2, 2004, from <http://www.eeoc.gov/facts/adaqa1.html>.

<sup>126</sup> *Ibid.*

<sup>127</sup> For more information, see EEOC. (2004, March 8). "Americans with Disabilities Act of 1990 (ADA) Charges." Retrieved on July 2, 2004, from <http://www.eeoc.gov/stats/ada.html>.

<sup>128</sup> SSA, EEOC, & U.S. Department of Justice, Civil Rights Division, 2002.

<sup>129</sup> EEOC, 1997.

<sup>130</sup> Dixon, K.A., Kruse, D., & Van Horn, C.E. (2003, March). "Restricted Access: A Survey of Employers About People With Disabilities and Lowering Barriers to Work." *Americans' Attitudes About Work, Employers and Government. Work Trends*. New Brunswick, NJ: John J. Heldrich Center for Workforce Development, Rutgers, The State University of New Jersey. Retrieved from <http://www.heldrich.rutgers.edu>.

<sup>131</sup> Ibid.

<sup>132</sup> Ibid.

<sup>133</sup> For example, the 2000 N.O.D./Harris Survey of Americans with Disabilities found that, among people with disabilities who are able to work, 56 percent were working in 2000, an increase from 46 percent in 1986. Harris Interactive, Inc. (2000b). *2000 N.O.D./Harris Survey of Americans with Disabilities*. Study No. 12384. New York: Harris Interactive, Inc.

<sup>134</sup> N.O.D., 2004a.

<sup>135</sup> Ibid.

<sup>136</sup> N.O.D. (2004b). "Detailed Results from the 2004 N.O.D./Harris Survey of Americans with Disabilities." Washington, DC: National Organization on Disability. Retrieved on August 25, 2004, from [http://www.nod.org/pdf/files/harris2004/harris2004\\_data.pdf](http://www.nod.org/pdf/files/harris2004/harris2004_data.pdf).

<sup>137</sup> U.S. Department of Labor. (2001, July). "Statistics About People with Disabilities and Employment." Retrieved from <http://www.dol.gov/odep/pubs/ek01/stats.htm>.

<sup>138</sup> EEOC. (1994, January). "Facts About Disability-Related Tax Provisions." Retrieved from <http://www.eeoc.gov/facts/fs-disab.html>.

<sup>139</sup> "Eligible small businesses" are those with \$1 million or less in gross receipts for the preceding tax year, or 30 or fewer full-time employees during the preceding tax year.

<sup>140</sup> White House Domestic Policy Council. (2004, March). "The President's New Freedom Initiative for People with Disabilities: The 2004 Progress Report, Executive Summary." Washington, DC: White House Domestic Policy Council. Retrieved on September 20, 2004, from <http://www.whitehouse.gov/infocus/newfreedom/newfreedom-report-2004.pdf>.

<sup>141</sup> EEOC. 2003. "New Freedom Initiative." Retrieved on September 20, 2004, from <http://www.eeoc.gov/initiatives/nfi/index.html>.

<sup>142</sup> An interim report will be available in fall 2004.

<sup>143</sup> For more information, see <http://www.yourtickettowork.com>.

<sup>144</sup> For state information about Employment Networks, see [http://www.ssa.gov/work/Ticket/ticket\\_info.html](http://www.ssa.gov/work/Ticket/ticket_info.html); for state information about State Vocational Rehabilitation Agencies, see <http://www.ssa.gov/work/ServiceProviders/StateTicketTracker.html>.

<sup>145</sup> SSA. (2001, April). *The Ticket to Work and Self-Sufficiency Program*. SSA Publication No. 05-10061, ICN 463262. Retrieved from <http://www.ssa.gov/pubs/10061.html>.

<sup>146</sup> For more information on the administration of the TTW program, see <http://www.yourtickettowork.com>.

<sup>147</sup> For more information about CAP Employment, see [http://www.tricare.osd.mil/cap/programs/programs\\_employment.cfm](http://www.tricare.osd.mil/cap/programs/programs_employment.cfm).

<sup>148</sup> For more information about CAP Program Accessibility, see [http://www.tricare.osd.mil/cap/programs/programs\\_access.cfm](http://www.tricare.osd.mil/cap/programs/programs_access.cfm).

<sup>149</sup> For more information about CAP System Accessibility, see [http://www.tricare.osd.mil/cap/programs/programs\\_system.cfm](http://www.tricare.osd.mil/cap/programs/programs_system.cfm).

<sup>150</sup> Personal Communication with Commissioner David Hanson and Deputy Commissioner Gil Selders, July 26, 2004.

<sup>151</sup> Chicago's Navy Pier is, "a multimillion dollar convention, cultural and recreation center and Chicago's most visited attraction." For more information, see <http://www.navypier.com>.

<sup>152</sup> National Disability Mentoring Day, a partnership activity between the U.S. Department of Labor's Office of Disability Employment Policy (ODEP) and the American Association of People with Disabilities, is a national event organized by local communities. It is designed to enhance internship and employment opportunities for people with disabilities by bringing them together with employers for a day of job shadowing and other hands-on career exploration activities. For people with disabilities, it is an opportunity to see the connections between school and work, evaluate personal goals, target career skills for improvement, explore possible career paths, and develop lasting mentor relationships. For employers, it is an opportunity to recruit interns, tap a pool of potential future employees, and learn more about the experience of disability. For more information, see [www.dmd-aapd.org](http://www.dmd-aapd.org).

<sup>153</sup> Personal Communication with Gil Selders, July 2004.

<sup>154</sup> Mayor's Office for People with Disabilities (MOPD). (2003, October 17). "National Disability Mentoring Day Matches Today's Workforce Visionaries with Tomorrow's Leaders." *Access Notes*. Retrieved from [http://egov.cityofchicago.org/webportal/COCWebPortal/COC\\_EDITORIAL/An101703.pdf](http://egov.cityofchicago.org/webportal/COCWebPortal/COC_EDITORIAL/An101703.pdf).

<sup>155</sup> For more information, see <http://www.usbln.com>.



<sup>156</sup> U.S. Business Leadership Network (USBLN). *2003 USBLN Exceptional Leadership Awards*. Retrieved on June 27, 2003, from [www.usbln.com/bestprac/2003awards.htm](http://www.usbln.com/bestprac/2003awards.htm).

<sup>157</sup> Sponsors include Pepsi Cola Bottling Company of Salisbury; Lower Shore Enterprises, Inc.; Perdue Farms Incorporated; Macron, Inc.; Peninsula Regional Medical Center; Beacon Technologies, Inc.; Avery Hall Insurance Group; SunTrust; Black & Decker; Capitol Securities Management, Inc.; Helvoet Pharma; Harvard Custom Manufacturing; Upper Shore Workforce Investment Board; W.L. Gore & Associates.

<sup>158</sup> For more about One-Stop Centers, see the description of Career Alliance, Inc. (Flint, MI).

<sup>159</sup> USBLN.

<sup>160</sup> QUEST: Quality, Understanding, Excellence, Success, Training.

<sup>161</sup> Personal Communication, Steven Serra, director, Recruitment and Examination Division, Office of Personnel Services and Benefits, MD Department of Budget and Management, August 31, 2004.

<sup>162</sup> Ibid.

<sup>163</sup> One-Stop Career Centers were established under the Workforce Investment Act (WIA) of 1998. WIA reforms federal job training programs and creates a new, comprehensive workforce investment system that is customer-focused, helps workers access the tools they need to manage their careers, and helps U.S. companies find skilled workers. One-Stop Career Centers are designed to provide a full range of assistance to jobseekers under one roof. These Centers exist in every state and offer training referrals, career counseling, job listings, and similar employment-related services. Customers can visit a center in person or connect to the center's information through personal computer or kiosk remote access. For more information about One-Stop Career Centers and where they are located in each state and local areas see the U.S. Department of Labor Web site [www.dol.gov/dol/topic/training/onestop.htm](http://www.dol.gov/dol/topic/training/onestop.htm).

<sup>164</sup> U.S. Department of Labor, Office of Disability Employment Policy. *Customized Employment Q and A*. Retrieved on September 9, 2004, from <http://www.dol.gov/odep/tech/employ.htm>.

<sup>165</sup> This process of course will be slightly different for people who want to be self-employed. Continuing education or training can be part of the individual work plan.

<sup>166</sup> Eligible applicants may be (1) recipients of SSI or SSDI; (2) participants in a day program or participants in facility-based or community employment and earning less than minimum wage; (3) participants in segregated employment and choosing to move to integrated competitive employment; (4) awaiting employment services and supports following a move from a residential facility, or as part of a plan to move into a community; (5) transitioning from, or preparing to transition from, secondary school under a transition plan under part B of the Individuals with Disabilities Education Act who, without access to customized employment

strategies, would likely be referred to one of the environments listed above; and (6) veterans and certain of their spouses that qualify under the Jobs for Veterans Act.

<sup>167</sup> Personal communication, July 9, 2004.

<sup>168</sup> Bill's story was chronicled in two CBS television movies: Emmy-award winning "Bill" (1981) and the sequel "Bill: On His Own" (1983). A documentary by Lane Wyrick entitled "Bill Sackter: A Special Spirit" is forthcoming in December 2004. Walz's book, *Unlikely Celebrity: Bill Sackter's Triumph over Disability*, was published in 1998 by Southern Illinois University Press.

<sup>169</sup> For more information, email her at [gretchen.berland@yale.edu](mailto:gretchen.berland@yale.edu).

<sup>170</sup> Iezzoni, L.I. (2002). Using Administrative Data to Study Persons with Disabilities. *The Milbank Quarterly*, 80(2): 347–79.

<sup>171</sup> Singer, S., Juang, A., Sage, B., Bergthold, L., & Osterhoff, R. "Regulating Medical Necessity Decision Making by Health Maintenance Organizations." Retrieved on September 9, 2004, from <http://www.hcfo.net/pdf/singer.pdf>.

<sup>172</sup> Singer, S., Bergthold, C., Vorhaus, S., Olson, S., Mutchinick, I., Goh, Y.Y., Zimmerman, S., & Enthover, A. (1999, August). "Decreasing Variation in Medical Necessity Decision-Making: Final Report to the California HealthCare Foundation." Stanford, CA: Center for Health Policy, Stanford University. Retrieved on September 9, 2004, from <http://www.chcf.org/documents/policy/medicalnec.pdf>.

<sup>173</sup> O'Day, B., & Corcoran, P.J. (1994). Assistive Technology: Problems and Policy Alternatives. *Archives of Physical Medicine and Rehabilitation*, 75:1065–9.

<sup>174</sup> Hanson, Neuman, & Voris, 2003.

<sup>175</sup> This is exemplified in Batavia, A.I. (1991). Of wheelchairs and managed care. *Health Affairs*, 18(6):177–82.

<sup>176</sup> Scheer, J., Kroll, T., & Neri, M. (2001, October 22). "Consequences of Delayed or Denied Access to Health Care Services: Perceptions of Individuals with Disabilities." Paper presented at the 129th Annual Meeting of the American Public Health Association, Atlanta, GA. Abstract retrieved on September 9, 2004, from [http://apha.confex.com/apha/129am/techprogram/paper\\_30183.htm](http://apha.confex.com/apha/129am/techprogram/paper_30183.htm).

<sup>177</sup> Hanson, Neuman, & Voris, 2003.

<sup>178</sup> Patrick, D.L. (1997). Rethinking Prevention for People with Disabilities Part I: A Conceptual Model for Promoting Health. *American Journal of Health Promotion*, 11(4): 257–60. Retrieved on July, 28, 2004, from <http://depts.washington.edu/cdpr/docs/AJPH1.pdf>.

<sup>179</sup> U.S. Department of Health and Human Services (HHS). (1991). *Healthy People 2000: National Health Promotion and Disease Prevention Objectives*. Pub. No. (PHS) 91-50213. Washington, DC: HHS, Public Health Service (PHS), Office of Disease Prevention and Health Promotion (ODPHP), pp. 39–42.

<sup>180</sup> HHS. 2004. “Healthy People 2010 Leading Health Indicators.” Retrieved from <http://www.healthypeople.gov/LHI>.

<sup>181</sup> Chapter 6 of *Healthy People 2010* lists 13 objectives covering a range of health goals. The first goal is data and surveillance and asks for standard questions to define disability among federal data sets. Here disability is viewed as another demographic variable that provides a method and rationale for examining differences in health and health care. See U.S. Department of Health and Human Services. (2000, November). *Healthy People 2010, 2nd ed. With Understanding and Improving Health and Objectives for Improving Health. 2 vols.* Washington, DC: U.S. Government Printing Office.

<sup>182</sup> DeJong, G., Palsbo, S.E., Beatty, P.W., Jones, G.C, Kroll, T, & Neri, M.T. (2002). “The Organization and Financing of Health Services for Persons with Disabilities.” *The Milbank Quarterly*, 80(2):261–301.

<sup>183</sup> Highsmith, N., & Somers, S. (2003, September). “Adults with Disabilities in Medi-Cal Managed Care: Lessons from Other States.” Oakland, CA: Med-Cal Policy Institute, California Health Care Foundation. Retrieved on June 9, 2004, from <http://www.chcf.org/documents/mcpi/access/MediCalDisabilitiesLessons.pdf> or <http://www.chcs.org>.

<sup>184</sup> The Supreme Court’s 1999 *Olmstead v. L. C.* decision requires states to provide services “in the most integrated setting appropriate to the needs of qualified individuals with disabilities.” Centers for Medicare & Medicaid Services. “Americans with Disabilities Act/Olmstead Decision” retrieved from <http://www.cms.hhs.gov/olmstead/default.asp>.

<sup>185</sup> The term “supportive housing” refers to a range of residential approaches designed to meet the needs of vulnerable populations, such as homeless persons or low-income frail elders who need assistance with long-term care, but who do not need intensive nursing services. Other terms to describe this approach include “service-enriched,” “service-enhanced,” “housing with services,” or “special needs housing.” See Sheehan, N.W.A., & Oakes C.E. (2004). *Public Policy Initiatives Addressing Supportive Housing: The Experience of Connecticut*. Paper prepared for Information Brokering for Long-Term Care, a project of the Center for Home Care Policy & Research, Visiting Nurse Service of New York; funded by The Robert Wood Johnson Foundation.

<sup>186</sup> NORCs are made up of dwellings that were not designated for older persons but where seniors have lived for most of their adult lives (“aging in place”). NORCs can be public housing, private apartment buildings, or any neighborhood with a high concentration of older persons who have aged in place.

<sup>187</sup> O’Hara, A., & Day, S. (2001, December). “Olmstead and Supportive Housing: A Vision for the Future (Consumer Action Series).” Princeton, NJ: Center for Health Care Strategies, Inc. Retrieved on August 13, 2004, from [http://www.chcs.org/usr\\_doc/supportive\\_housing.pdf](http://www.chcs.org/usr_doc/supportive_housing.pdf).

<sup>188</sup> The “Independent Living Movement” was born out of both civil rights and consumer activism movements of the 1960s. The goal of this movement is for people with disabilities to control their own lives, become self-empowered and socially and economically productive, achieve self-direction, and have the opportunity to live in permanent, independent, affordable, and accessible housing. See “Independent Living” on The Center for an Accessible Society Web site. Retrieved on August 27, 2004, from <http://www.accessiblesociety.com/>; also see DeJong, G. (1979). “Independent Living: From Social Movement to Analytic Paradigm.” *The Archives of Physical Medicine and Rehabilitation*, 60:435–446. Retrieved on August 30, 2004, from [http://www.impactcil.org/phil\\_history/dejong.htm](http://www.impactcil.org/phil_history/dejong.htm).

<sup>189</sup> Independent Living Centers (ILCs) are typically nonresidential, private, nonprofit, consumer-controlled, community-based organizations providing services and advocacy by and for persons with all types of disabilities. For more information and a list of ILCs in various states across the states, see the Independent Living USA Web site. Retrieved on August 30, 2004, from <http://www.ilusa.com/links/ilcenters.htm>.

<sup>190</sup> Association of University Centers on Disabilities. (2003, August 21). “New Freedom Initiative: Medicaid Demonstrations Act of 2003: Summary.” Retrieved on August 18, 2004, from [http://www.aucd.org/Medicaid/NFI\\_legislation\\_summary.htm](http://www.aucd.org/Medicaid/NFI_legislation_summary.htm).

<sup>191</sup> “Money Follows the Individual” *Rebalancing Initiative*. Retrieved August 30, 2004, from <http://www.cms.hhs.gov/newfreedom/0303mfir.pdf>.

<sup>192</sup> For additional information and examples of state strategies, see Crisp, S., Eiken, S., Gerst, K., & Justice, D. Promising Practices: (2003, September 29). “Money Follows the Person and Balancing Long-Term Care Systems: State Examples.” Washington, DC: prepared for U.S. Department of Health and Human Services (DHHS), Center for Medicare and Medicaid Services (CMS) by Medstat Research Policy Division. Retrieved on September 7, 2004, from <http://www.cms.hhs.gov/promisingpractices/mfp92903.pdf>.

<sup>193</sup> Phillips, B., Mahoney, K., Simon-Rusinowitz, L., Schore, J., Barrett, S., Ditto, W., Reimers, T., & Doty, P. (2003, June). “Lessons from the Implementation of Cash and Counseling in Arkansas, Florida, and New Jersey.” Princeton, NJ: Mathematica Policy Research, Inc. Retrieved on August, 26, 2004, from <http://aspe.hhs.gov/daltcp/reports/cclessons.htm>.

<sup>194</sup> The defining characteristic of a consumer-directed model of service delivery is that it allows people with disabilities considerable choice and control over how support services are provided and by whom. Clients may employ anyone they choose, including family members. See Doty, P., Benjamin, A.E., Matthias, R.E., & Franke, T.M. *In-Home Supportive Services for the Elderly and Disabled: A Comparison of Client-Directed and Professional Management Models of Service Delivery (Non-Technical Summary Report)*. Washington, DC: U.S. Department of Health and Human Services (HHS), Office of the Assistant Secretary for Planning and

Evaluation (ASPE), Office of Disability, Aging, and Long-Term Care Policy (DALTCP). Retrieved on August 12, 2004, from <http://aspe.hhs.gov/daltcp/reports/ihss.htm>.

<sup>195</sup> Mitchell, G.R., January 30, 2003. "Cash & Counseling: Consumer Choices, Family Reimbursements." Retrieved from the Empowering Caregivers Web site on August 12, 2004, from <http://www.care-givers.com/DBArticles/pages/viewarticle.php?id=77>.

<sup>196</sup> Phillips et al., 2003, Retrieved on August 26, 2004, from <http://aspe.hhs.gov/daltcp/reports/cclessons.htm>.

<sup>197</sup> Mahoney, K.J., Simone, K., & Simon-Rusinowitz, L. (2003, Fall). "Early Lessons from the Cash and Counseling Demonstration and Evaluation." *Consumer Direction in Long-Term Care*, pp. 41–46.

<sup>198</sup> Dale, S., Brown, R., Phillips B, Schore, J., & Carlson, B.L. (2003, November 19). "The Effects of Cash and Counseling on Personal Care Services and Medicaid Costs in Arkansas." *Health Affairs Web Exclusives* (supplement), pp. W3-566 to W3-575. Retrieved from <http://content.healthaffairs.org/cgi/reprint/hlthaff.w3.566v1.pdf>.

<sup>199</sup> Boston College. *New National Project Aims to Improve Services, Quality of Life for Medicaid Elderly and Disabled*. Retrieved on August 11, 2004, from [http://www.bc.edu/bc\\_org/rvp/pubaf/04/medicaid.html](http://www.bc.edu/bc_org/rvp/pubaf/04/medicaid.html); also see [www.cashandcounseling.org](http://www.cashandcounseling.org).

<sup>200</sup> Palsbo, S., Beatty, P., Parker, P., & Duff, C. (2004, January). "Minnesota Disability Health Options: Expanding Coverage for Adults with Physical Disabilities." Princeton, NJ: Center for Health Care Strategies, Inc. (CHCS). Retrieved on June 7, 2004, from [http://www.chcs.org/publications3960/publications\\_show.htm?doc\\_id=208392](http://www.chcs.org/publications3960/publications_show.htm?doc_id=208392); also see Minnesota Department of Human Services. "Minnesota Disability Health Options." Retrieved on August 3, 2004, from [http://www.dhs.state.mn.us/main/groups/healthcare/documents/pub/DHS\\_id\\_006272.hcsp](http://www.dhs.state.mn.us/main/groups/healthcare/documents/pub/DHS_id_006272.hcsp).

<sup>201</sup> Medical Assistance is the name of Minnesota's Medicaid Program. Minnesota offers several health care programs to help people with disabilities pay for health care costs. For information, see the Department of Human Services Web site at [http://www.dhs.state.mn.us/main/groups/healthcare/documents/pub/DHS\\_id\\_006249.hcsp](http://www.dhs.state.mn.us/main/groups/healthcare/documents/pub/DHS_id_006249.hcsp).

<sup>202</sup> Wisconsin Department of Health and Family Services. (2001, April). "The Wisconsin Partnership Program: An Integrated Care Model for People who are Elderly and for People with Physical Disabilities (Working Paper)." Retrieved on June 28, 2004, from [http://www.chcs.org/usr\\_doc/WisconsinPartnership.pdf](http://www.chcs.org/usr_doc/WisconsinPartnership.pdf); also see Wisconsin Department of Health and Family Services. "Wisconsin Partnership Program." Retrieved on August 2, 2004, from <http://www.dhfs.state.wi.us/WIpartnership>.

<sup>203</sup> Under a Medicaid waiver the Federal Government allows or grants states permission to waive certain federal requirements to operate a specific kind of program. They often are used to authorize managed care, or alternative delivery or reimbursement systems. In general, federal

law allows states to enact three types of Medicaid waivers: Program Waivers (1915 (b), 1915 (c), 1915 (b)/1915 (c) concurrent waivers); Research and Demonstration Waivers (115 waivers-general); and Health Insurance Flexibility and Accountability (1115 Demonstration Initiative). For more information about waivers, see Center for Medicare and Medicaid Services, *Medicaid Waivers and Demonstrations*, available at <http://www.cms.hhs.gov/medicaid/waiver1.asp>.

<sup>204</sup> The Wisconsin Partnership Program distinguishes “multidisciplinary” from “interdisciplinary.” Multidisciplinary means bringing several disciplines to bear on an issue or problem, but the experts from each discipline do not necessarily collaborate. Interdisciplinary means experts from several disciplines interact to arrive at a course of action in response to an issue or problem.

<sup>205</sup> Elder Care of Wisconsin, Madison; Community Living Alliance, Madison; Community Care for the Elderly, Milwaukee; and Community Health Partnership in Eau Claire.

<sup>206</sup> Tillery, 2004. Also see Arkansas Department of Human Services, Division of Aging and Adult Services, available at <http://www.state.ar.us/dhs/aging/pubs.html>.

<sup>207</sup> *Coming Home: Affordable Assisted Living* (Coming Home) is a 13-year, \$14.3 million national program created in 1992 by the Robert Wood Johnson Foundation (RWJF) and NCB Development Corporation to develop affordable models of assisted living, with a focus on smaller and rural communities and low-income seniors. See the National Program Report. Retrieved from <http://www.rwjf.org/reports/npreports/cominghomee.htm>.

<sup>208</sup> NCB Development Corporation, a national nonprofit organization that fosters community development by providing technical assistance and predevelopment financing to nonprofit community-based organizations nationwide, is affiliated with National Cooperative Bank. For more information, on see <http://www.ncbdc.org>.

<sup>209</sup> For a list of Coming Home Assisted Living demonstration projects in other states, see <http://www.rwjf.org/programs/npoDetail.jsp?id=CRE>.

<sup>210</sup> See endnote 203 for information about waivers.

<sup>211</sup> Arkansas State Legislature. (2001, April 30). “The Arkansas Assisted Living Act.” Act 1230 of 2001. Retrieved on August 17, 2004, from <http://www.arkleg.state.ar.us/ftproot/acts/2001/htm/act1230.pdf>.

<sup>212</sup> Assisted living is a concept that combines apartment living with supportive personal and health care services to allow older people to maintain their independence and dignity while receiving a high level of care and support. See U.S. Department of Housing and Urban Development. (2003, April 2). “Assisted-Living Facility First for Arkansas.” Retrieved on August 18, 2004, from <http://www.hud.gov/local/ar/library/archives/goodstories/2003-04-02.cfm>.

<sup>213</sup> NCB Development Corporation. (2002, December 9). “Arkansas Opens One of The Nation’s First True Affordable Assisted Living Residences (Press Release).” Retrieved on August 17, 2004, from <http://www.ncbdc.org/ncbdc/contents.nsf/index.htm?OpenPage&link=/ncbdc/contents.nsf/docname/aalindustrynewsdoc.htm>.

<sup>214</sup> NCB Development Corporation. (2003, May 12). “Two Arkansas Coming Home Programs Awarded Low-Income Housing Tax Credits (Press Release).” Retrieved on August 17, 2004, from <http://www.ncbdc.org/ncbdc/contents.nsf/index.htm?OpenPage&link=/ncbdc/contents.nsf/docname/aalindustrynewsdoc.htm>.

<sup>215</sup> Sheehan & Oakes, 2004.

<sup>216</sup> Ibid.

<sup>217</sup> Ibid.

<sup>218</sup> Ibid.

<sup>219</sup> Ibid.

<sup>220</sup> For a detailed description of the program, see Vladeck, F. (2004). *A Good Place to Grow Old: New York’s Model for NORC Supportive Service Programs*. New York, NY: United Hospital Fund. In New York City, NORC-SSPs generally are located in housing complexes where 45 percent of units have heads of household who are 60 years old or older, with a minimum of 250 such households or a minimum count of 500 households that fit that description.

<sup>221</sup> Social work services are provided by trained social workers and may include such things as information and referral, assistance with benefits and entitlements, care management and service coordination, and education for caregivers, among others.

<sup>222</sup> These include help with management of chronic conditions as well as acute situations, help in navigating the health care system, blood pressure monitoring, flu shots, and a number of other health promotion, prevention, and wellness activities. The goal is to help older residents maintain their independence and continue living at home.

<sup>223</sup> For more information about these organizations see Chapter 3.

<sup>224</sup> For more information about Toastmasters International, see <http://www.toastmasters.org>.

<sup>225</sup> Harris Interactive, Inc., 2000b, p. 5.

<sup>226</sup> Ibid.

<sup>227</sup> Ibid., p. 8.

<sup>228</sup> Ibid., p. 11.

<sup>229</sup> See City of Phoenix, “Adaptive Recreation Services,” at <http://www.phoenix.gov/PRL/adrecsvc.html>.

<sup>230</sup> River Rampage was funded by a grant from the U.S. Department of Education from 1994 to 1996.

<sup>231</sup> City of Phoenix. 2004. “Adaptive Recreation Services, River Rampage.” Retrieved on August 10, 2004, from <http://www.phoenix.gov/PRL/adrecsvc.html#RIVER>.

<sup>232</sup> Personal Communication, Linda Tuck, August 11, 2004.

<sup>233</sup> Personal Communication, Linda Tuck, August 11, 2004.

<sup>234</sup> City of Phoenix, 2004.

<sup>235</sup> Personal Communication, Betty Siegel, August 2004.

<sup>236</sup> The Experiential Education Initiative (EEI) is an outgrowth of the recommendation to increase opportunities for people with disabilities to pursue careers in the arts through internships from the National Forum on Careers in the Arts held in June 1998 at The John F. Kennedy Center for the Performing Arts and sponsored by the National Endowment for the Arts, U.S. Department of Education, U.S. Department of Health and Human Services, the Social Security Administration, and The John F. Kennedy Center for the Performing Arts.

<sup>237</sup> The Connors Foundation is a private family foundation.

<sup>238</sup> EEI is targeted to people who don’t go through the traditional pathways (e.g., don’t go to college), but go through “back doors” to pursue a career in the arts. EEI interns are referred and prescreened by partner agencies/service providers—for example, Arc of Montgomery County, Arc of D.C., SEEC Montgomery County, Mount Vernon Lee Enterprises (MLVE).

<sup>239</sup> The Kennedy Center. (2002, Fall). “Removing Barriers: Careers in the Arts for Persons with Disabilities.” *National Education Review: A Biannual Report on the Education Programs of the John F. Kennedy Center for the Performing Arts*, Vol. IV.

<sup>240</sup> For more information on AXIS Dance Company, see <http://www.axisdance.org>.

<sup>241</sup> Previously, choreography was done in-house.

<sup>242</sup> Among AXIS’ most notable performances are the 2002 Olympic Arts Festival in Salt Lake City, Utah, and a residency in Novosibirsk, Siberia, in 1995. AXIS cocurated and coplanned the International Festival of Wheelchair Dance in 1997 with Dance Umbrella, a nonprofit dance company. In November 2004, AXIS performed at Meredith Monk’s 40th Anniversary Celebration in New York City.



<sup>243</sup> AXIS received numerous Isadora Duncan Awards during 2000 and 2001, was honored with a “Goldie for Dance” from the *San Francisco Bay Guardian*’s Outstanding Local Discovery Award in 2000, and was awarded by Mayor Jerry Brown with a “Key to Creativity” in 2002 in honor of their artistic achievements throughout the previous 15 years.

<sup>244</sup> The company will have spent 14 weeks on tour by the end of 2004, and has already scheduled 8 weeks of touring for 2005.

<sup>245</sup> Dance disciplines include Contact Improvisation, Laban-based work, contemporary dance techniques, somatics and body work, physical theater, Authentic Movement, and choreography and composition.

<sup>246</sup> AXIS has received grants from the National Endowment for the Arts, Rockefeller Foundation’s MAP Fund, William and Flora Hewlett Foundation, Creative Work Fund, Wallace Alexander Gerbode Foundation, Walter and Elise Haas Fund, San Francisco Foundation, Christopher Reeve Paralysis Foundation, and Zellerbach Family Fund. Other awards include Performing Arts Fellowships from the Barkley Fund, Choreographer’s Fellowships from the City of Oakland and the Bay Area Fund for Dance, California Arts Council Exemplary Arts grant, and two nominations for a Cal Arts/Alpert Award in the Arts, which recognizes mid-career artists creating work of value.

<sup>247</sup> For more information on FaithWays, see the National Alliance for the Mentally Ill Web site at <http://mn.nami.org/faithways.html>.

<sup>248</sup> For more information on eSlate™ in Harris County, see <http://www.harrisvotes.org/index2.htm> (retrieved on September 16, 2004).

<sup>249</sup> The task force members are listed at [http://www.harrisvotes.org/non\\_frames/taskforce-geninfo.htm](http://www.harrisvotes.org/non_frames/taskforce-geninfo.htm) (retrieved on September 16, 2004).

<sup>250</sup> The eSlate™ units are manufactured by K\*TEC Electronics under a contract manufacturing agreement with Hart InterCivic, Inc.

<sup>251</sup> The voter outreach and education campaign was designed by Hart InterCivic, Inc. and implemented by the Hill and Knowlton public relations firm.

<sup>252</sup> “Early Voting” was adopted in Texas in the mid-1990s. Harris County conducts early voting 14–17 days before Election Day and allows registered voters to vote at any one of 30 locations throughout Harris County.

<sup>253</sup> U.S. Bureau of the Census, Census 2000. All percentages are rounded.

<sup>254</sup> The information contained in this description of the San Mateo County strategic plan was gleaned from the “Strategic Plan for Services for Older Adults and Adults with Disabilities 2000” and conversations with Shea Muller, a Planner with the San Mateo County Aging and Adult Services Division. For more information, contact Shea Muller at 650-573-3527.

<sup>255</sup> Nolden, S., Climaco, C., Bonjorni, J., & Rich, K. (2002). "Updating the Low-Income Housing Tax Credit (LIHTC) Database: Projects Placed in Service through 2000." Prepared for: U.S. Department of Housing and Urban Development, Office of Policy Development and Research. Retrieved on October 4, 2004, from <http://www.huduser.org/Datasets/LIHTC/report952k.pdf>.