

Opportunities for Community Development Finance in the Disability Market



Bringing together the community development sector, disability service organizations, and financial institutions to strengthen economic opportunities for Americans with disabilities.

FEATURES

- ▶ Trends and opportunities in the disability housing market
- ▶ Programs, research, and legislation aimed at promoting asset-building for the disability consumer
- ▶ Efforts to increase the employment of people with disabilities

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The views expressed in this publication are solely those of the authors and do not necessarily represent those of the Federal Reserve Bank of Boston or the Federal Reserve System.

Foreword

At the 20th Anniversary of the Americans with Disabilities Act (ADA), there is much to celebrate regarding the economic gains of individuals with disabilities. The protections against discrimination based on disability created by the passage of the ADA in 1990 and the ADA Amendment Act in 1998 have opened up opportunities in housing and employment, significantly increased the accessibility of public places, and helped us all focus on people and their talents, rather than their differences. But there is still much to be done to promote self-sufficiency for Americans with disabilities and the kinds of opportunities in employment, savings, and housing that are enjoyed by their peers without disabilities. Individuals with disabilities still report lower incomes, higher unemployment, and lower usage of savings, investment, and other financial services and products.

An emerging group of stakeholders is learning to combine the health and human services expertise of disability service organizations, the development finance and asset-building knowledge of the community development sector, and the financial resources and market knowledge of the financial services industry to create products, services, programs, and policies designed to strengthen economic opportunities for Americans with disabilities.

The business case for getting involved is simple. This is a large market, representing over 54 million people (35 million who report a severe disability) with hundreds of billions of dollars in purchasing power. In terms of public policy, expanding economic opportunity for people with disabilities would promote equality and could lead to cost savings by helping individuals work and save at higher rates. This market is not only underserved (e.g., few savings and investment products are designed for it) but also underdeveloped (e.g., funding streams for housing are fragmented); thus, there is ample opportunity here for community development finance organizations to apply their market-building expertise.

In February 2010, the Board of Governors of the Federal Reserve System, the Federal Reserve Bank of Boston, The Disability Opportunity Fund, and Wall Street Without Walls sponsored a forum in Washington, DC titled *Opportunities for Community Development Finance in the Disability Market* to discuss how to leverage the resources of different sectors to bring more Americans with disabilities into the financial mainstream. The Boston Fed solicited a series of papers on housing, asset building, and employment to serve as background material for the conference. Those papers are presented here.

The trend in disability housing toward supports and services being provided in community-based residences or within one's own home has resulted in a large unmet demand for affordable, accessible, community-based housing. David Braddock opens the publication by showing trends in federal, state, and municipal spending for services to people with disabilities. The data identify a strong shift away

from institutional and nursing facility care toward community-based residential services and supports, especially for intellectual and developmental disabilities. He argues that this shift has resulted in unmet demand for community residential services that the community development finance field can help address. Charles Hammerman and Samantha Bennett also point to the large unmet demand for affordable and accessible housing and suggest that the largest barrier to meeting this demand is capital. Like Braddock, they argue that Community Development Financial Institutions (CDFIs) are uniquely positioned to provide the needed capital and expertise. Sue Swenson explains that a barrier to developing the community-based housing market for people with developmental disabilities is a scarcity of data supporting market segmentation. She provides sketches of disability consumers to illustrate the range of preferences and needs among these individuals. She also explains how stakeholders like CDFIs, other housing experts, and disability advocates can apply traditional marketing disciplines to create market segmentations with currently available public data.

Several challenges currently limit the asset-building potential of people with disabilities. Johnette Hartnett and Tobey Davies discuss how asset and income limits for public benefits are disincentives to efforts to work and save. Serena Lowe and Alexander Reid also discuss these disincentives and explain that there are few savings tools designed for people with disabilities that have the kind of flexibility, portability, and tax advantages available to other Americans. In terms of efforts to strengthen asset building, Hartnett and Davies describe the preliminary results of a series of new asset-building efforts focused on the disability consumer: data collection, community-based partnerships between disability services organizations and community development groups to deliver free tax preparation assistance and asset building programs, and research investigating the effects of these types of programs and partnerships on the market participation of consumers. Lowe and Reid discuss current legislative proposals aimed at tackling policy disincentives and expanding savings options for this market.

Improving economic outcomes must involve increasing the employment rate for people with disabilities, which has remained largely unchanged over the last 20 years. Andrew Imparato, Andrew Houtenville, and Robin Shaffert describe the legal protections against discrimination in employment launched with the passage of the ADA and the ADA Amendment Act and point out that employment rates for people with disabilities have not significantly improved despite these legislative protections. They go on to describe new federal and private efforts to improve employment outcomes and put out a call for further action. Charles Riley argues that the public and nonprofit sectors will not be able to significantly improve the employment problem on their own, but that the participation of the private sector is necessary. He makes the case that companies should take action not because it is the “right thing to do,” but rather because a disability-forward corporate policy is good for business. He also describes a strategy for how companies, with support from nonprofit organizations, can tap the disability market.

Together with the conference presentations, this publication promotes a conversation on how community development organizations, the disability sector, and private companies including financial institutions can work together to strengthen economic outcomes for people with disabilities. We are pleased to provide a spotlight for the efforts and ideas described in the papers. Our hope is that highlighting them will spark additional conversations and motivate others to join the networks of people and organizations working to implement meaningful change.

A number of people and organizations helped make this paper series possible. We would like to thank Charlie Hammerman and Amy Ogulnick at The Disability Opportunity Fund; John Nelson, Sarah Gordon, and Robert Zdenek at Wall Street Without Walls; and John Moon at the Board of Governors of the Federal Reserve System for their help in identifying authors. Thanks to Charles Riley for his editorial assistance. Thanks also to our reviewers at the Boston Fed: Marques Benton, Mary Hughes Bickerton, Prabal Chakrabarti, Caroline Ellis, DeAnna Green, and Ana Patricia Muñoz. Finally, we would like to thank the Ford Foundation, AT&T, and Prudential Financial, Inc. for their financial support of this research.

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Public Spending for Disability in the United States: 1997-2006

David Braddock, University of Colorado

Spending by federal, state, and local units of government constitutes a large proportion of the resources available to assist people with disabilities in the United States. These funds pay for health care, income maintenance, special education, vocational rehabilitation and training, and long-term care including housing and related residential support services. Funds are allocated directly to individuals as well as to schools, health care organizations, and tens of thousands of nonprofit and proprietary disability services organizations.

This paper describes an ongoing study of trends in public-sector disability spending and services from 1997 to 2006. The study was funded in part by the federal government's National Institute on Disability and Rehabilitation Research. The principal purpose of the study is to identify trends in federal, state, and local governmental spending for services for persons with intellectual and developmental disabilities (I/DD), mental illness, and physical disabilities. In addition to presenting a brief statistical summary of annual spending and services trends, this paper provides additional information on long-term care, the most extensively funded disability service in the United States. The need for long-term care services will continue to grow rapidly as the number of older Americans rises.

The findings of this study illustrate the increasing size and growth rate of the disability market as well as a strong, continuing shift away from the use of institutional and nursing facility care toward more individualized community residential and personal support services. Long waiting lists for community-based services, however, indicate that demand far exceeds supply (Kaiser Commission on Medicaid and the Uninsured, 2009; Ng, Harrington, and Kitchener, 2010). The continuing shift in public-private funding toward community residential services and supports, as well as the emerging use of residential support technologies, will help meet the growing demand in future years. The community development finance field can play a particularly important role in helping to significantly expand the provision of affordable community-based housing and related supports for people with disabilities.

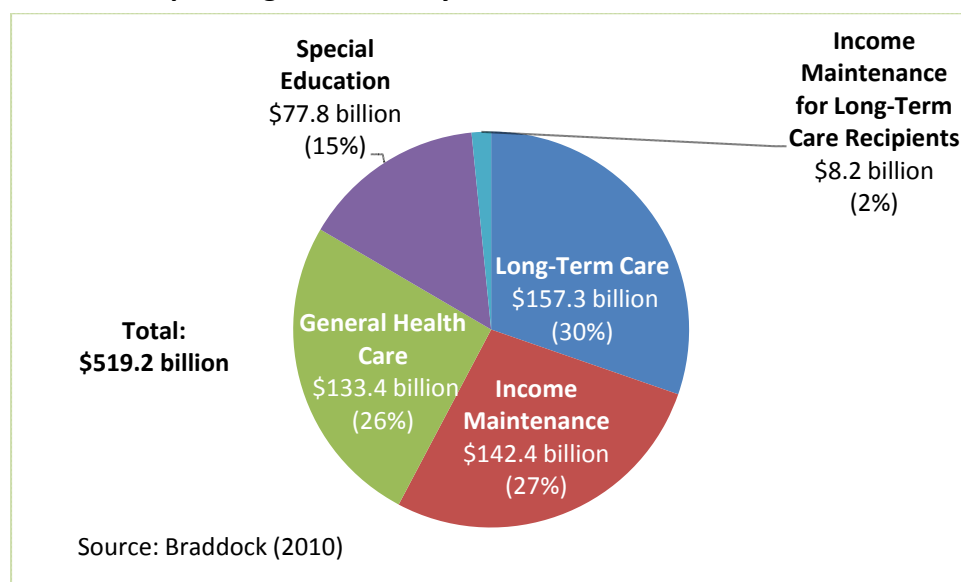
Overview of Public Spending and Services for Disability

Public spending for disability programs in the United States totaled \$519.2 billion in fiscal year 2006 (see Figure 1) (Braddock, 2010). This constituted 11 percent of total federal, state, and local spending in the U.S. that year. Thirty percent of disability spending (\$157.3 billion) was allocated for long-term care; 27 percent for income maintenance (29 percent when long-term care–related income maintenance support is included); 26 percent (\$133.4 billion) for health care; and 15 percent (\$77.8 billion) for special education. The \$8.2 billion for long-term care-related income maintenance includes federal Supplemental Security Income (SSI) benefits for Home and Community Based Services (HCBS) Waiver participants with disabilities (\$4.5 billion) and SSI State Supplement payments for community-based services (\$3.6 billion). The Medicaid HCBS Waiver program, authorized under Title XIX of the Social

Security Act, allows participating states to develop residential alternatives for individuals with I/DD who would otherwise require care in a nursing facility, state mental hospital, or state institution.

Figure 1

U.S. Public Spending for Disability in 2006



Sixty-three percent of spending for disability services and income maintenance (\$329.1 billion) in fiscal year 2006 was allocated by the federal government; 28 percent (\$142.7 billion) by state governments; and 9 percent (\$47.3 billion) by local units of government, primarily school districts. A total of 53.6 million individuals with disabilities were assisted by public sector financial commitments in 2006 (see Table 1). This is a duplicated count and includes income maintenance assistance to 21.4 million individuals; general health care assistance to 17.3 million individuals; long-term care assistance to 7.9 million individuals; and assistance to 7.0 million children and youth in special education programs.

Total disability spending advanced 35 percent in inflation-adjusted terms, from \$381.6 billion in 1997 to \$519.2 billion in 2006. Spending grew 3.5 percent per year above the rate of inflation during this decade. The most rapid annual growth was 6.7 percent from 2001 to 2002, and the slowest average annual growth was 0.6 percent from 2005 to 2006. Disability-related health care spending increased 56 percent in inflation-adjusted terms from 1997 to 2006, growing from \$85 billion to \$133 billion (see Figure 2). Spending grew 48 percent for special education, 31 percent for income maintenance, and 21 percent for long-term care services.

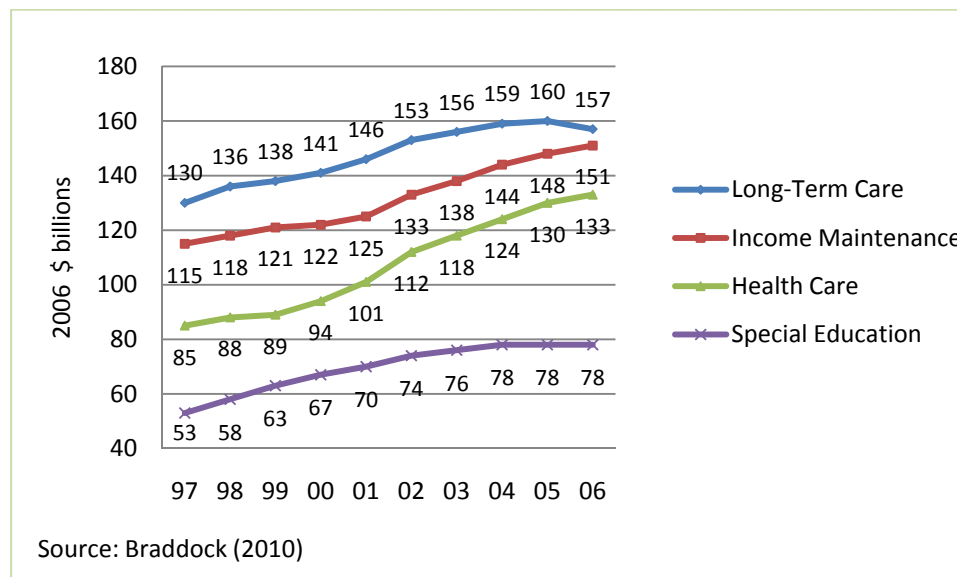
Table 1

Disability Services and Income Maintenance Recipients in 2006

Program	Recipients
Income Maintenance	21,398,280
Supplemental Security Income (SSI)	5,898,959
SSI State Supplement	2,293,430
Social Security Disability Insurance (DI)	6,356,980
Adult Disabled Child (ADC)	745,190
Veterans' Compensation	2,683,117
Food Stamps	2,616,000
Housing and Urban Development (HUD)	804,604
Health Care	17,300,620
Medicare	6,586,337
Medicaid	8,861,890
Veterans' Medical Care	1,852,393
Special Education	7,006,421
Long-Term Care (LTC)	7,929,536
Community LTC & Related Services	6,929,602
I/DD State Agency Programs	1,494,716
Mental Illness State Agency Programs	3,351,118
Medicaid HCBS Waiver: Physical Disability	207,778
Medicaid Home Health Care	725,856
Medicaid Personal Care	624,063
Related Services	
Vocational Rehabilitation (VR)	202,983
Independent Living	266,580
Veterans' Rehabilitation	55,469
HUD Construction	1,038
Institutional LTC	999,934
Nursing Facilities (all disabilities)	882,710
I/DD Institutions (public/private 16+)	68,293
Mental Illness Institutions	48,931
Total Recipients	53,634,857

Figure 2

Disability Spending in the U.S. by Activity Category, Adjusted for Inflation, 1997-2006



There was significant variation in the growth of public spending among different states from 1997 to 2006. The most rapid average annual growth rates in disability spending were in Arizona, Nevada, Alaska, New Mexico, and Idaho (between 5.3 and 6.7 percent growth). These states were also in the top 20 nationally in average annual general population growth during this period. The five states with the slowest annual growth rates in disability spending were Connecticut, Massachusetts, North Dakota, Michigan, and Illinois (between 2.1 percent and 2.6 percent growth in spending). These states ranked in the bottom third in general population growth and grew less than one percent. The general population declined between 2005 and 2006 in Michigan.

The number of participants receiving long-term care services grew rapidly from 1997 to 2006, increasing by 24 percent from 6.4 million individuals to 7.9 million individuals. This growth was primarily attributable to expansion in the number of recipients of home health care, personal care, and HCBS Waiver services. The number of disabled recipients of health care services increased even more rapidly, growing by 49 percent from 11.6 million individuals in 1997 to 17.3 million individuals in 2006. Medicaid and Medicare beneficiaries constituted 89 percent of all disabled health care beneficiaries and increased 45 percent and 43 percent, respectively, during 1997 to 2006. Income maintenance beneficiaries increased 24 percent, growing from 17.2 to 21.4 million individuals. Disability Insurance (DI) and SSI beneficiaries, constituting 58 percent of all disabled recipients, increased by 30 percent and 28 percent, respectively, during the 10-year period. Special education student enrollment jumped 19 percent, from 5.9 million to 7.0 million students. The most rapid growth in student enrollment from 1997 to 2006 was 44 percent among children and youth with developmental disabilities (intellectual disability, autism, traumatic brain injury, and developmental delay); there was growth of 15 percent among students with

physical disabilities; and 5 percent among students with emotional disturbance. The number of students with autism, a subcomponent of developmental disabilities, increased 345 percent from 1997 to 2006.

Increased spending for disability-related services is attributable to broader legislative mandates for services in special education, community residential supports, health care, and income maintenance. National Health Expenditures as a share of the GDP increased from 13.5 percent in 1998 to 15.8 percent in 2006 (Centers for Medicare and Medicaid Services, 2009). Implementation of the Americans with Disabilities Act of 1990 and the Individuals with Disabilities Education Act (IDEA) has led to increased services and supports for many children and adults with disabilities. Increasing life spans of people with disabilities has also led to growing demand for such services (Braddock, Hemp, Rizzolo, 2008). Class action litigation has promoted alternatives to the institutionalization of people with disabilities (Herr, 1983; Herr, Arons, & Wallace, 1983; Parry, 2010).

Growth of Community Long-Term Care Services and the Medicaid HCBS Waiver

In 2006, the nation budgeted 51 percent of public long-term care disability funds for community residential services, defined here as homes, apartments, and facilities that served 15 or fewer persons per setting, and related vocational, family support, and service coordination programs. Forty-nine percent of total long-term care spending was allocated for state and private institutions and nursing facilities serving 16 or more persons at each site. Twenty-four states committed less than 50 percent of their long-term care financial resources for community services activities in 2006. Only seven states—Alaska, Arizona, California, Maine, Minnesota, New Mexico, and Vermont—committed more than 65 percent of total long-term care funds to community services. However, all states significantly increased the proportion of funds allocated to community services versus state-operated institutions and nursing facility care over the decade 1997-2006.

The I/DD field is transforming from an institution- and nursing facility-dominated service delivery system to a community residential and family support system more rapidly than its counterparts in mental health and physical disability (Braddock, 1992). From 1997 to 2006, the proportion of community services long-term care funding for persons with I/DD long-term care increased from 68 percent to 78 percent. The proportion of spending committed to community mental health care versus state hospital or nursing facility care increased from 51 percent to 56 percent, and the proportion of spending for community services for persons with physical disabilities increased from only 19 percent to 25 percent.

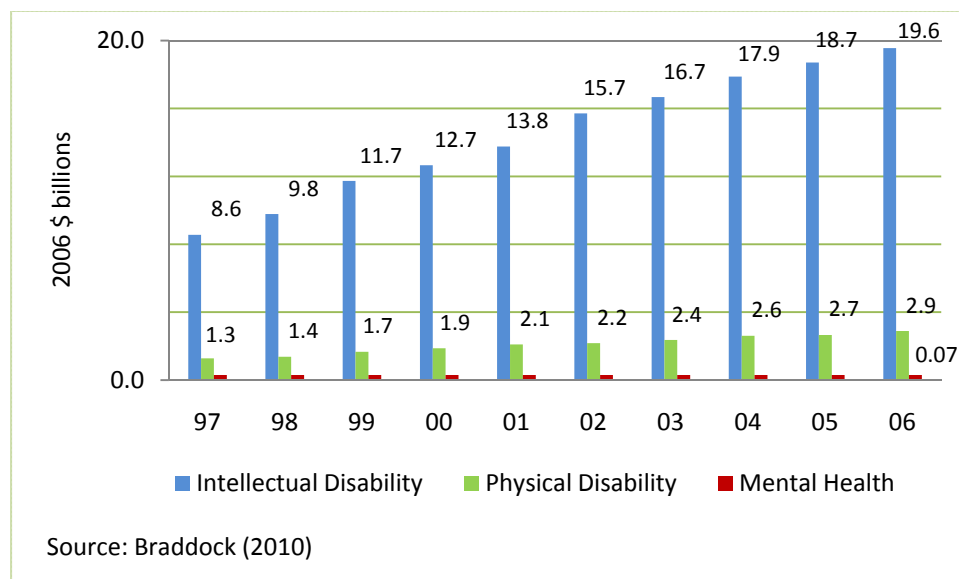
Two factors largely account for the more modest growth of community service funding for persons with physical disabilities and mental illness compared with I/DD. First, financial commitments for HCBS Waiver programs are smaller for physical disability and mental illness. Second, although there is pressure to reduce utilization of state psychiatric hospitals and avoid high per diem costs, this often leads to inappropriate placements in nursing facilities and in congregate care boarding homes (see Bazelon Center for Mental Health Law, 2009; Fisher, Geller, White, and Altaffer, 1995).

Rapidly increasing funding for community residential services in I/DD is largely attributable to the growth of the Medicaid HCBS Waiver (see Figure 3). Adjusted Waiver spending advanced 10 percent per

year for persons with I/DD from 1997 to 2006 (Braddock, 2010). The growth of HCBS Waiver spending for mental health services grew from a markedly smaller base than that for persons with I/DD, but advanced 37 percent per year during the same period.

Figure 3

Growth of Home and Community Services Waiver Spending by Disability Group, 1997-2006



Community residential services spending for persons with I/DD first surpassed consolidated I/DD spending for institutions and nursing facilities in 1989 (Braddock, Hemp, and Rizzolo, 2008). Institutional and nursing facility spending for persons with I/DD declined one percent per year during the decade 1997 to 2006. In contrast, I/DD community services spending increased five percent per year. Class action litigation and the implementation of the Americans with Disabilities Act have been major contributing factors in stimulating the growth of community services and supports, particularly for persons with mental disabilities (Braddock, Hemp, & Rizzolo, 2004).

Community mental health spending also grew five percent per year during 1997 to 2006, albeit from a much smaller base than I/DD spending. However, mental health spending for state institutions and nursing facility settings, in contrast to I/DD services in such settings (which contracted significantly), increased by three percent per year. Most of the mental health increase in spending for institutional and nursing facilities was attributable to nursing facilities. Community residential services spending for persons with physical disabilities grew an average of four percent per year on an adjusted basis from 1997 to 2006. Institutional spending for nursing facilities for this population was essentially static, advancing only 0.4 percent per year between 1998 and 2001 and then declining 1.4 percent per year between 2002 and 2006.

Consolidated inflation-adjusted long-term care spending for persons with mental and physical disabilities in institutions and nursing facilities increased only 0.2 percent per year from 1997 to 2006. However, community services spending grew rapidly, at 5 percent per year. Total consolidated inflation-

adjusted community services spending for disability services surpassed institutional spending in 2005. In summary, services and funding for persons with disabilities are gradually moving toward smaller, more individualized community settings. Consequently disability-related community development finance opportunities are poised to continue growing comparatively rapidly in the future.

Market Opportunities

Spending on disability-related services and income maintenance is growing. As a percentage of all federal, state, and local governmental expenditures, total disability spending advanced by 12.4 percent from 1997 to 2006 (Office of Management and Budget, 2009). However, institutional and nursing home long-term care spending increased by only an inflation-adjusted two percent, and the number of recipients in institutional settings actually decreased by nine percent. In contrast, community-based long-term care spending advanced 52 percent during 1997 to 2006, and the number of participants in these settings increased 31 percent. Community services growth is strongest in the I/DD field, while nursing facility care continues to be extensively utilized for people with physical disabilities and mental illness. However, the use of community and family support-based settings for physical disability and mental health care is poised to increase as these community support models become increasingly emphasized in legislation and through the courts (Sulzberger, 2010).

Long waiting lists for community residential services are commonplace today, and access remains a significant problem in many parts of the country for people with mental and physical disabilities (Kaiser Commission on Medicaid and the Uninsured, 2008a; Prouty, Smith, and Lakin, 2007). Many people with disabilities are currently living with aging caregivers who themselves require, or will soon require, community residential support services. In the absence of an adequate supply of such services, the caregiver and those cared for are both at risk of being inappropriately placed in nursing facilities.

One emerging innovation addressing the community support needs of people with I/DD and aging populations is “smart home” technology. The technology has the potential to improve service quality, reduce staff turnover, and possibly cut staffing costs. Staff turnover in I/DD out-of-home residential care settings is typically very high, often above 50 percent per year (Mitchell and Braddock, 1994).

Residential support technology can help consumers live safely in community residential settings or in their own homes. Smart home technology includes: 1) motion, temperature, door break, and carbon monoxide sensors and floor pressure pads; 2) personal emergency response systems; 3) personal digital assistants customized to facilitate activities of daily living; 4) selective access to appliances; 5) security and safety systems; and 6) web-based care information systems.

Medicaid financial support could be critical to national adoption of technology supports in residential care. Smart home technology has already received support from the state Medicaid program in Indiana, and Minnesota, Ohio, and West Virginia are considering Medicaid participation. For additional information on the use of smart home technology for I/DD see Imagine (2008), Rest Assured (2008), and Responsive Solutions, Inc. (2008); in aging, see Elite Care (2002) and Health Sense (2010). The cognitive disability market for residential services and technology support is sizeable. More than 21

million people in the United States currently have a significant cognitive disability, which includes I/DD, severe and persistent mental illness, brain injury, and Alzheimer's disease (Rizzolo and Braddock, 2008). Careful evaluation of smart home technology and demonstration programs are required prior to widespread adoption of this innovation in service provision. However, residential support technologies carefully tailored to the needs of individual consumers with disabilities have the potential to enhance consumer self-direction, promote healthy lifestyles, and increase social interaction.

Current financing models for disability-related community residential services are underdeveloped and require integrating fragmented funding from federal, state, local, and private-sector sources. The community development finance sector may be able to help develop a more systematized and efficient funding system by providing start-up and patient capital, carrying some of the financial risk, developing financing models, and evaluating process and consumer outcomes. To develop viable models, the community development finance field will need to establish new partnerships with disability services organizations and improve its understanding of available federal, state, and local funding for support services required by people with disabilities. Community development finance organizations have a growing and potentially key role to play in helping our nation meet the growing demand for affordable, accessible, community-based housing for people with disabilities.

David Braddock is the Coleman-Turner chair and professor in psychiatry in the University of Colorado School of Medicine, executive director of the Coleman Institute for Cognitive Disabilities, and associate vice president of the four-campus University of Colorado System. The author gratefully acknowledges the contributions of research associates Richard Hemp and Diane Coulter in the data collection process.

Technical Note on Data Sources

General Health Care

Medicaid data were obtained primarily from the Centers for Medicare and Medicaid Services (2009) and the Kaiser Commission on Medicaid and the Uninsured (2007a); for Medicare, from the Centers for Medicare and Medicaid Services (2008), and for veterans' health care services spending, from the U.S. Department of Veterans Affairs (2007) and S.V. Panangala (2008).

Income Maintenance

Social Security Disability Insurance (DI) data were obtained from the Social Security Administration (2007a); Supplemental Security Income (SSI) data were obtained from the Social Security Administration (2006b); data for Adult Disabled Child benefits under Title II of the Social Security Act were obtained from the Social Security Administration (2006a); and SSI state supplement data were obtained from the Social Security Administration (2007b). Sources for veterans' compensation included the U.S. Department of Veterans Affairs (2007); sources for food stamp data included Barrett (2006) and

Wolkwitz (2007); and HUD rental subsidies were estimated based on data from the U.S. Department of Housing and Urban Development (2004).

Long-term Care

State-by-state data for I/DD long-term care services provided by state agencies were obtained from Braddock, Hemp, and Rizzolo (2008) and for mental health long-term care services provided by state agencies, the National Association of State Mental Health Program Directors (2009) and the Substance Abuse and Mental Health Services Administration (2009). Nursing facility data were obtained from the Centers for Medicare and Medicaid Services (Office of the Actuary, 2007) and the American Health Care Association (2009).

Data on other components of long-term care in the states came from Heinsohn (2009a, 2009b), Eiken and Burwell (2008, 2007), and the Kaiser Commission on Medicaid and the Uninsured (2007b, 2008). Data on other community-based Medicaid programs including personal assistance, health care, and targeted case management were obtained from Burwell, Sredl, and Eiken (2007) and the Kaiser Commission on Medicaid and the Uninsured (2009). Data on construction funding come from the U.S. Department of Housing and Urban Development (2007). Data on vocational rehabilitation services were obtained from the U.S. Department of Education, Rehabilitation Services Administration (2009).

Special Education

Regular education per pupil cost data by state were obtained from the U.S. Census Bureau for years 2000 through 2008 (2008) and from Zhou and Johnson (2008). Nationwide excess special-education cost factors were obtained from Chambers, Parrish, Lieberman, and Wolman (1998) and from Chambers, Parrish, and Harr (2002). Federal Individuals with Disabilities Education Act (IDEA) funding consisted of Part B, Section 611 (93 percent of federal special education funding to the states); Part B, Pre-school, Section 619 (3 percent); and Part C early intervention funding (4 percent) (U.S. Department of Education, 2009). The source of state government spending for special education was the U.S. Census Bureau for years 2000 through 2008 (2008) and a direct survey of 15 states' special education departments that did not report data to the Census Bureau. Local government special education spending in each state was estimated based on total special education spending less federal and state government special education spending.

We used an "excess costs" approach to estimate special education spending nationally and in individual states. Total excess special education cost *above* general education costs per pupil was \$8,186 nationally for the academic year 1999 to 2000, the latest year for which data were available (Chambers, Shkolnik, and Perez, 2003). Projecting these costs forward and adjusting for inflation, special education excess costs per pupil were estimated to be \$11,987 in 2006. The intervening years' costs were also estimated using this methodology.

The excess cost per pupil for students with emotional disturbance in 2006 was \$13,934; for I/DD (mental retardation, autism, traumatic brain injury, and developmental delay), \$14,970; and for physical/learning disability, the excess cost was \$11,088 per pupil. All other disabilities were included in a broad physical/learning disability category, which included multiple disabilities; hearing, orthopedic, visual, other health impairments; deaf-blindness; and general learning disabilities. We used the excess per pupil costs for each disability category to estimate total public special education spending at the federal, state, and local level.

References

American Health Care Association. 2009. *Trends in nursing facility characteristics*.

<http://www.ahcancal.org/>.

Barrett, A. 2006. *Characteristics of food stamp households, fiscal year 2005*. Alexandria, VA: U.S. Department of Agriculture, Food and Nutrition Service.

Bazelon Center for Mental Health Law. June 24, 2009. *Still waiting...the unfulfilled promise of Olmstead*. Washington, DC: Judge David L. Bazelon Center for Mental Health Law.

Braddock, D. Disability spending in the U.S. 2010. Boulder: University of Colorado School of Medicine, Department of Psychiatry.

Braddock, D. 1992. Community mental health and mental retardation services in the United States: A comparative study of resource allocation. *American Journal of Psychiatry*, 149(2).

Braddock, D., R. Hemp, and M.C. Rizzolo. 2004. State of the states in developmental disabilities: 2004. *Mental Retardation*, 42(5).

———. 2008. *The state of the states in developmental disabilities*. 7th ed. Washington, DC: American Association on Intellectual and Developmental Disabilities.

Burwell, B., K. Sredl, and S. Eiken. August 10, 2007. *Medicaid long-term care expenditures in fiscal year 2006*. Cambridge, MA: Thomson Healthcare.

Centers for Medicare and Medicaid Services. 2008. *Medicaid health care expenditure data set*. Baltimore: Centers for Medicare and Medicaid Services.

———. January 2009. *National health expenditure (NHE) amounts by type of expenditure and source of funds: Calendar years 1965-2018*. Baltimore: Centers for Medicare and Medicaid Services.

<http://www.cms.hhs.gov/NationalHealthExpendData>.

Chambers, J.G., T.B. Parrish, and J.J. Harr. March 2002. *What are we spending on special education services in the United States, 1999-2000?* (Report 02-01) (Updated September 2002). Palo Alto, CA: Center for Special Education Finance (CSEF).

Chambers, J., T. Parrish, J. Lieberman, and J. Wolman. February 1998. *What are we spending on special education in the U.S.?* CSEF Brief No. 8. Palo Alto, CA: CSEF.

Chambers, J.G., J. Shkolnik, and M. Perez. June 2003. *Total expenditures for students with disabilities, 1999-2000: Spending variation by disability.* Palo Alto, CA: CSEF.

Eiken, S. and B. Burwell. August 20, 2007. *Medicaid HCBS waiver expenditures, fiscal year 2001 through fiscal year 2006.* Cambridge, MA: Thomson-MEDSTAT.

———. September 26, 2008. *Medicaid HCBS waiver expenditures, fiscal year 2002 through fiscal year 2007.* Cambridge, MA: Thomson Reuters.

Elite Care. 2002. *Extended family residences, an alternative to assisted living: Oatfield Estates.* Milwaukie, OR: Elite Care. <http://www.elite-care.com/oatfield.html>

Fisher, W.H., J.L. Geller, C.L. White, and F. Altaffer. 1995. Serving the seriously mentally ill in the “least restrictive alternative”: Issues from a federal court consent decree. *Administration and Policy in Mental Health*, 22(4).

Healthsense. 2010. *Technology for better senior living.* Mendota Heights, MN: Author. [accessed July 19, 2010: <http://www.healthsense.com>].

Heinsohn, D. March 3, 2009a. *Centers for independent living 704 report data for 1997, 1998, 1999, and 2000.* Houston, TX: Independent Living Research Utilization Unit.

———. January 5, 2009b. *Centers for independent living 704 report data for 2006.* Houston, TX: Independent Living Research Utilization Unit.

Herr, S.S. 1983. *Rights and advocacy for retarded people.* Lexington, MA: Lexington Books.

Herr, S.S., S. Arons, and R.E. Wallace, Jr. 1983. *Legal rights and mental health care.* Lexington, MA: Lexington Books.

Imagine! 2008. Technology Solutions for Consumers. Lafayette, CO: Imagine!
<http://www.imaginecolorado.org/techSolCons.htm>.

Kaiser Commission on Medicaid and the Uninsured. September 2007a. *Long-term services and supports: the future role and challenges for Medicaid*. Washington, DC: The Henry J. Kaiser Family Foundation. <http://www.kff.org/>.

———. 2007b. *Medicaid home and community-based service programs: Data update*. Washington, DC: The Henry J. Kaiser Family Foundation. <http://www.kff.org/>.

———. 2008. *Medicaid home and community-based service programs: Data update* Washington, DC: The Henry J. Kaiser Family Foundation. <http://www.kff.org/>.

———. 2009. Kaiser Family Foundation State Health Facts (Medicaid Services): *Medicaid spending and enrollees for HCBS waivers (2005), home health and personal assistance (1999-2005), waiting lists (2005, 2006, 2007) and total Medicaid spending (2005, 2006, 2007)*. <http://www.kff.org/>.

Kaiser Commission on Medicaid and the Uninsured (KCMU) and the University of California at San Francisco (UCSF). December 2008. *Medicaid 1915(c) home and community-based service programs: Data update*. <http://www.statehealthfacts.org/>.

Mitchell, D. and D. Braddock. 1994. Compensation and turnover of direct care staff in developmental disabilities residential facilities in the United States II: Turnover. *Mental Retardation*, 32(1).

National Association of State Mental Health Program Directors. 2009. *State mental health authority spending and revenue data for 2006*, Excel database file.

Ng, T., C. Harrington, and M. Kitchener, M. 2010. Medicare and Medicaid in long-term care. *Health Affairs*, 29(1).

Office of the Actuary, Centers for Medicare and Medicaid Services. September 2007. *2004 state estimates, state estimates by state of residence, all payers, nursing home care*. Baltimore: Office of the Actuary, Centers for Medicare and Medicaid Services. <http://www.cms.hhs.gov/>.

Office of Management and Budget. 2009. *Budget of the United States government: Fiscal year 2010*. Washington, DC: Office of Management and Budget.

Panangala, S.V. July 29, 2008. *Veterans' medical care: Fiscal year 2009 appropriations*. Washington, DC: Congressional Research Service Report for Congress.

Parry, J.W. 2010. *Civil mental disability law, evidence and testimony*. Chicago: American Bar Association.

Prouty, R., G. Smith, and K. Lakin. 2007. *Residential services for persons with developmental disabilities: Status and trends through 2006*. Minneapolis: University of Minnesota, College of Education and Human Development.

Responsive Solutions, Inc. 2008. *Sound Response*. Madison, WI: Responsive Solutions, Inc.
<http://www.waisman.wisc.edu:8000/cedd/SoundResponse/index.html>.

Rest Assured. 2008. *Caring people, remarkable technology*. Lafayette, IN: Rest Assured.
<http://www.restassuredsystem.com/>.

Rizzolo, M.K. and D. Braddock. 2008. People with Cognitive Disabilities, in *The engineering handbook of smart technology for aging, disability and independence*, eds. S. Helal, M. Mokhtari, and B. Abdulrazak. Hoboken, NJ: John Wiley & Sons.

Social Security Administration. June 2006a. *Social Security bulletin, annual statistical supplement*. Baltimore: Social Security Administration.

———. September 2006b. *State assistance programs for SSI recipients, January 2006*. Baltimore: Office of Research, Evaluation, and Statistics.
http://www.ssa.gov/policy/docs/progdesc/ssi_st_asst/2006/index.html.

———. August 2007a. *Annual statistical report on the Social Security Disability Insurance Program, 2006*. Washington, DC: Office of Research, Evaluation, and Statistics.

———. September 2007b. *SSI annual statistical report, 2006*. Baltimore: Office of Research, Evaluation, and Statistics. http://www.socialsecurity.gov/policy/docs/statcomps/ssi_asr/.

Substance Abuse and Mental Health Services Administration. 2009. *Uniform reporting system output tables for mental health statistics*. Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration. <http://mentalhealth.samhsa.gov/cmhs/>.

Sulzberger, A.G. June 24, 2010.. U.S. Appeals Court lifts stay on relocating mentally ill. *The New York Times*.

U.S. Census Bureau. April 2008. *Public education finances: 2006*. Washington, DC: Governments Division.
<http://www2.census.gov/govs/school/06f33pub.pdf>

U.S. Department of Education. January 2009. *Twenty-eighth annual report to Congress on the implementation of the Individuals with Disabilities Education Act (fiscal year 2006)*. Washington, DC: Office of Special Education and Rehabilitative Services, Office of Special Education Programs.

U.S. Department of Education, Rehabilitation Services Administration. 2009. *Vocational rehabilitation data for fiscal year 2006*. <http://rsamis.ed.gov/choose.cfm>.

U.S. Department of Housing and Urban Development. 2004. *A Picture of subsidized households: Project, agency, and state summaries: Fiscal year 2000*. Washington, DC: U.S. Department of Housing and Urban Development. <http://www.huduser.org>.

———. 2007. *Section 811 Supportive Housing for Persons with Disabilities*. Washington, DC: U.S. Department of Housing and Urban Development. <http://www.hud.gov/content/releases/pr06-003summary.pdf>.

U.S. Department of Veterans Affairs. 2007. *Annual benefits report fiscal year 2006*. Washington, DC: Veterans Benefits Administration. <http://www.vba.va.gov>.

Wolkwitz, K. 2007. *Characteristics of Food Stamp households, fiscal year 2006*. Alexandria, VA: U.S. Department of Agriculture Food and Nutrition Service.

Zhou, L., and F. Johnson. April 2008. *Revenues and expenditures for public elementary and secondary education: School year 2005-06*. Washington, DC: U.S. Department of Education, National Center for Education Statistics.

The Disability Housing Market: Opportunity for Community Development Finance as the Americans with Disabilities Act Turns 20

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A home is more than just an address, more than just a place to hang your hat. For many of us, the first time we feel independent is when we sign our first lease, buy our first set of dishes, and pay our first bills. For many, the most strenuous part of finding a place to live is meeting the right real estate agent, or finding a home with enough bathrooms or one with a decent-size kitchen and adequate sunlight.

For low-income people with disabilities, their concerns go beyond counter space and hardwood floors to finding housing that is safe, affordable, and accessible. For far too long, many people with disabilities have been deprived of the opportunity to rent or own their own home. Many have been excluded from obtaining housing vouchers, and some simply have no access to the limited housing options that are currently available. For many, it has been a dream without much likelihood of coming true.

Over the last 40 years, many articles, progress reports, and statistics have addressed this critical issue. Yet there is no coherent public policy to address the housing needs of people with disabilities. Congress has struggled since the passage of the Vocational Rehabilitation Act in 1973 to develop a working plan that empowers people with disabilities who want to live independently to do so. Several other laws and regulations have been enacted since then in the hope of protecting people with disabilities and helping them find safe, affordable, accessible housing.

Although there is no coherent approach to providing housing, the demand for it is strong. There are more than 41 million noninstitutionalized Americans living with some form of disability. More than 23 million are between the ages of 18 and 65 (Cornell University, 2007). It is the inadequate supply that has ultimately hindered those with disabilities from attaining housing.

How Is the “Disability Market” Measured?

Statistical information concerning disabilities is collected through several different venues. The American Community Survey (ACS), Cornell University’s *Disability Status Report*, and the University of Colorado’s Coleman Institute for Cognitive Disabilities are a few of the sources.

The ACS, working with the U.S. Census Bureau and the Department of Commerce, hopes to sample close to three million homes a year. Currently the ACS strives to “provide data users with timely information each year on demographic, housing, social, and economic statistics that can be compared across states, communities, and population groups” (Bjelland, Erickson, and Lee, 2008). The ACS is

¹ A version of this paper appears in *Community Development Investment Review*, Volume 5, Issue 3, 2009, Federal Reserve Bank of San Francisco, available at http://www.frbsf.org/publications/community/review/vol5_issue3/index.html.

administered annually and is intended to eventually replace the decennial Census. The ACS defines disabilities in a general way as a “long-lasting physical, mental, or emotional condition.” Working from information and data collected from the ACS, the Cornell *Disability Status Report* classifies individual disabilities into six separate categories: sensory, physical, mental, go-outside-home, self-care, and employment.

Whereas the ACS provides statistics for various disabilities, the Coleman Institute for Cognitive Disabilities focuses on “mental retardation and developmental disabilities, acquired brain injury, Alzheimer’s disease, and severe and persistent mental illness” (Braddock). The Coleman Institute’s mission is “to catalyze and integrate advances in science, engineering, and technology to promote the quality of life and independent living . . . of over 20 million American citizens—seven percent of the U.S. population”—living with cognitive disabilities. Since 1991, the Coleman Institute has gathered information and undertaken data analysis related to cognitive disabilities. Although the distribution of statistics is not the Institute’s main function, it willingly shares the useful information it has acquired.

How Big is the Market?

By analyzing data from the ACS, the Coleman Institute, and Cornell University’s *Disability Status Report* as well as other sources, we can see that disabled housing is an expanding market that represents underserved individuals and families. The data show that this market is growing exponentially. Consider the following:

Wounded Veterans of Iraq and Afghanistan

According to a published report from the John F. Kennedy School of Public Policy at Harvard, of the 1.4 million men and women deployed to Iraq and Afghanistan, nearly one-half will need medical attention from the Veterans Administration (VA) when they return. In addition, as a result of medical advances, the ratio of wounded soldiers to fatalities in these theaters is four to eight times higher than in any previous conflict (Blimes, 2007).

Autism

According to the website Autism Speaks: “A new study published October 5, 2009, in the American Academy of Pediatrics’ journal *Pediatrics* found a parent-reported autism prevalence rate of one in every 91 American children, including one in 58 boys. The study used data gathered as part of the 2007 National Survey of Children’s Health (NSCH), a national survey directed and funded by the Health Resources and Services Administration (HRSA) and Centers for Disease Control and Prevention (CDC).”

Baby Boomers

In the next 10 years, the major wave of baby boomers will be entering their seventies (Friedman, 2009).

It is estimated that the current senior population of 34 million will double over the next 20 years. What do these statistics have to do with disabilities? In 2007, 25 percent of Americans between the ages of 65 and 74 reported one or more disabilities, and 50 percent of Americans age 75 and older reported one or more disabilities (Bjelland, Erickson, and Lee, 2008).

A substantial percentage of individuals living with disabilities are considered “hidden” and are excluded from these statistics and analyses. Some, if not most, of these men and women are living with aging parents, even though they may be qualified to reside on their own or within supported living programs.

The 2005 U.S. Department of Housing and Urban Development (HUD) report on worst-case housing used 2004 Social Security Administration data to estimate that there were more than one million low-income adults with disabilities living in households with worst-case housing needs, defined as households with incomes falling below 50 percent of median area income who are paying more than half of their income for housing or are living in severely substandard housing. The report showed that more than 60 percent of unassisted very low-income households in which there is an adult member with a disability have worst-case housing needs, one of the highest proportions among low-income groups.

People with Disabilities are a Low-Income Target Market

Many people with disabilities live in poverty. For many who receive public support, even that is not enough to raise their incomes above the poverty rate. Cornell University reports that there are 22 million people between the ages of 16 and 64 in the United States with one or more disabilities (Cornell 2007). The Bureau of Labor Statistics reported that in December 2009, 18.6 percent of working-age individuals with disabilities were employed, compared to 63.3 percent of persons with no disability. The U.S. Census Bureau reports that those who do work typically earn about \$7,000 less per year than workers with no disability. The annual income of households with a wage earner who has a disability is \$26,500 less than households without a person with a disability (Cornell 2007). Moreover, researchers found that 24.7 percent of working-age Americans with disabilities lived in poverty compared to 9.0 percent of those without disabilities (Bjelland, Erickson, and Lee, 2008). These dramatic discrepancies are long-standing and continue to separate Americans with disabilities from their peers without disabilities.

Individuals who do not or cannot work experience even greater economic challenges. More than half of the population in the United States between 18 and 65 and who have disabilities rely on Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) as their only source of income. Of these 11.9 million people:

- 6.5 million people receive SSDI only. The average SSDI payment in 2008 was \$12,048/year or 116 percent of the Federal Poverty Guidelines for one person.
- Four million people receive SSI only. The average SSI payment in 2008 was \$5,724/year or 55 percent of the Federal Poverty Guidelines for one person.

- 1.5 million people receive both SSDI and SSI because their SSDI payment falls below the state's SSI payment threshold. The average SSI payment in these cases is \$2,082/year, bringing the annual income of these individuals "up to" 135 percent of the Federal Poverty Guidelines.

Note: These figures relate to the Federal Poverty Guidelines (FPG) and not the Area Median Household Income statistic, which is much higher than the FPG.

In addition to receiving public transfer payments that are far below Median Household Incomes in every state, individuals with disabilities must restrict their assets to qualify for these benefits. They cannot accumulate any more than \$2,000 in assets other than their house, car, and a life insurance policy (capped at \$1,500). Thus government programs can actually keep people with disabilities in poverty. This policy is based on the old notion that individuals with disabilities are unable to work and therefore must rely on others (such as family members) for support.

There is a "chicken or egg" conundrum when it comes to poverty and people with disabilities: Those living in poverty are more likely to have a disability and those with disabilities are more likely to live in poverty. Regardless of which came first, individuals with disabilities must have access to economic tools to escape poverty, achieve homeownership, and accumulate assets to improve their standard of living.

Can the System Work More Efficiently?

The challenge is to identify an approach that will efficiently deliver financial and other resources. Existing affordable housing programs at the federal, state, and local levels do not necessarily work in concert with disabilities programs, and they should. Existing housing programs can be tweaked to combine more easily with existing "disability" housing rental subsidies to increase the supply of available housing for people with disabilities. A simple and current example is the federal government's Neighborhood Stabilization Program (NSP). According to the HUD website, NSP funds are aimed at "the purchase and redevelopment of foreclosed and abandoned homes and residential properties." The problem is that HUD never thought to incorporate people with disabilities into the program. At present, more than a year after the NSP funds were delivered, we have found that some local government housing agencies are still sitting on unused NSP funds. These same agencies are also holding on to the Nursing Home Transition and Diversion (NHTD) Medicaid Waiver rent subsidy, which allows individuals with disabilities to live in the community through a rental voucher system. Rather than let the NSP dollars go to waste, we have suggested that the local housing authorities convert the foreclosed and abandoned homes into rental units for individuals with disabilities, who can use the Medicaid Waiver to pay the rent.

In 1990, Congress passed two important laws for low-income renters with disabilities: The Americans with Disabilities Act (ADA), and the Cranston-Gonzalez National Affordable Housing Act. According to the ADA: "Physical or mental disabilities in no way diminish a person's right to fully

participate in all aspects of society,” and further, “the continuing existence of unfair and unnecessary discrimination and prejudice denies people with disabilities the opportunity to compete on an equal basis and to pursue those opportunities for which our free society is justifiably famous, and costs the United States billions of dollars in unnecessary expenses resulting from dependency and nonproductivity” (The U.S. Equal Employment Opportunity Commission, 2009). Section 811 of the Cranston-Gonzalez National Affordable Housing Act (the Supportive Housing for Persons with Disabilities program) provides “funding exclusively to nonprofit developers building and operating housing for low-income households with disabilities” (National Alliance on Mental Illness, 2004).

Both laws were expected to make a tremendous difference in the lives of the disabled and their families. The ADA has made strides to help the disabled community by legally prohibiting discrimination in relation to work and housing opportunities, but Section 811 has seemingly fallen short of Congress’ original vision. The lack of new funding, the cost of renewing vouchers, and the elimination of project-based capital has crippled the Section 811 budget.

In 1999, the U.S. Supreme Court handed down the *Olmstead v. Lois Curtis and Elaine Wilson* decision, citing the unlawful confinement of disabled persons as a clear violation of the ADA. Today, ten years after the Olmstead decision, “more than 500,000 people who have mental illness other than dementia live in nursing homes,” the majority of whom could and should live independently if they were given the appropriate support (National Council on Disability, 2003).

The Disability Opportunity Fund—Filling the Gap

The Disability Opportunity Fund (DOF), a community development financial institution (CDFI), was created in 2007 to help improve the delivery of affordable housing. A market study commissioned by The DOF in 2007 found that there is not enough government funding to meet the needs of organizations (for-profit and nonprofit developers, social services agencies, and hospitals) interested in developing affordable housing for people with disabilities. The market study also found that those who successfully developed affordable housing for the disabled relied on multiple capital sources, usually including local, state, and federal government programs, the Federal Home Loan Bank, CDFIs, banks, and occasionally, their own earned income. As we had expected, the market study revealed that a lack of capital is the biggest restraint on the development of safe, accessible, affordable housing for the disabled.

CDFIs focus on the development of programs and strategies to meet the needs of low-income communities. Their mission is to make loans to entities that are unable to get loans from traditional banking institutions. They provide a range of products, including comprehensive credit, investment, banking, and development services. Some CDFIs are chartered banks, others are credit unions, and many operate as self-regulating, nonprofit institutions that gather private capital from a range of community-minded investors.

The DOF focuses exclusively on disability projects. To date, it has acted as a loan fund in creating housing solutions for eleven people with disabilities. We have both originated loans and bought a participation in a loan originated by a fellow CDFI. In the participation, we provided \$100,000 of

\$685,000 mini-perm financing for a newly constructed home in Darien, Connecticut, for six young adults who have developmental disabilities. The home provides the six residents with permanent housing in an environment that allows them to participate in their shared interests of sporting, social, volunteer, religious, and work activities. A professional full-time staff assists the residents in making choices, enjoying everyday life, achieving goals, living with dignity, and taking care of their own needs.

In addition to this loan, The DOF originated structured financing of two single-family houses in Tennessee for five low-income residents who have developmental disabilities. The first portion of the loan allows three individuals to remain in their shared home through more efficient financing, while the second portion allows two of the residents to obtain better financing and remain in their home as well. Providing affordable capital and creating reasonable and fiscally responsible loan repayment strategies ensures that these individuals can continue to live independently in the community.

Debt, Equity, and Technical Assistance

In the last two years alone, The DOF has been asked to develop financing for more than 40 projects in 17 different states. The composite-required financing is well over \$100 million and consists of both debt and equity. Most, if not all, of the future residents qualify as low-income.

Debt

The DOF regularly receives requests for bridge (or gap) financing. For example, a nonprofit on Long Island, New York, has applied for a \$350,000 loan with a 6 percent interest rate and a 5-year term. These funds would help retrofit existing units and allow two people with disabilities to live independently. The nonprofit has already secured the necessary government funding to support the residents and pay the debt service.

In Chicago, there is a need for a line of credit that could be used by for-profit developers to retrofit unused space in existing market-rate rental apartment buildings. The space will be converted into accessible, affordable housing units for people with disabilities. The city is prepared to provide rental subsidies for the units.

There is also a growing market for housing solutions for our returning soldiers from Iraq and Afghanistan. Those men and women who are wounded return to the United States and receive their treatment at a military hospital. Two major housing benefits are administered by the VA: A 25 percent guarantee on a VA mortgage and a fund for retrofitting homes to make them accessible.

One problem with the two VA programs, however, is that it takes a long time to establish eligibility. The length of time is particularly problematic, since the first few months of dealing with a new disability are extremely challenging. The DOF hopes to fix this problem by providing short-term financing to veterans. Consider this scenario: An injured Navy SEAL in San Diego has finished his medical treatment and is ready to buy a home. However, he is still awaiting word from the VA, which has not yet approved his eligibility for benefits. If he finds a house in the meantime, The DOF will provide him with the

necessary financing for closing. Then, once the serviceman becomes “VA eligible,” The DOF will be repaid by a conventional financial institution, which will issue a standard VA loan to the newly designated “veteran.” The DOF has identified approximately 2,000 to 3,000 servicemen and -women who could use this type of program.²

Equity

In light of the soft real estate market around the country, many developers have contacted The DOF seeking equity investments in either unfinished or unsold condominium units or homes. In return, the developers would set aside units of housing to be designated for people with disabilities. We have developed certain models that could yield an 8 to 12 percent annual return on these types of investments.

Technical Assistance

In addition to providing capital, The DOF continues to offer technical assistance in raising awareness of the resources available to develop affordable, accessible housing. During the market study, comments by key stakeholders suggested that many service organizations and housing developers are relatively self-taught when it comes to developing housing for the disabled. These service providers and developers simply recognized a demand in the communities they served or implemented required set-asides, and thus took the initiative on their own. They have relied on any number of information resources, including their own trial and error, inadequate government guidelines, end-user feedback, and other developers.

To promote better communication and coordination among the players, The DOF has organized and moderated several roundtable discussions hosted by the Federal Reserve Banks of San Francisco and Chicago, the New York Stock Exchange, and Delaware’s State Council for People with Disabilities. In addition, The DOF was invited by Virginia’s Department of Behavioral Health and Developmental Services to introduce the work of CDFIs as a possible leveraging solution to an \$18 million state budget set-aside to move 150 residents from state-run institutions into the community. Finally, The DOF has spent the last year working with the New York State Office of Mental Retardation and Developmental Disabilities to introduce it to the power of CDFI financing and discuss how to better coordinate programming among various agencies. Currently, more than 15 state agencies serve people with disabilities but their efforts are not well coordinated and many of the benefits and services they offer are not well known by potential clients.

² Author conversation with Noel Koch, Deputy Undersecretary of Defense, U.S. Department of Defense, office of Secretary of Defense Wounded Warrior Care and Transition Policy, December 2009.

The Future Is Looking Bright(er)

Public policies that have evolved in the hope of providing housing for the disabled have already been initiated by HUD, which remains in charge of Section 8 and 811 housing. HUD is currently working closely with the Department of Health and Human Services to connect people with disabilities living in institutions to HUD housing vouchers that would allow them to live in the community. President Barack Obama has designated 2010 the “Year of Community Living.” Through the National Affordable Housing Trust Fund Act of 2007, the president has asked for \$1 billion to produce, preserve, and rehabilitate 1.5 million affordable homes over the next ten years. Housing for low-income families, including housing for the disabled, will account for 67.5 percent of those homes.

Moreover, the proposed Frank Melville Supportive Housing Investment Act aims to amend Section 811 by speeding up processing requirements. Along with a change of pace, this act also aims to make Section 811 housing more affordable and available, specifically for people with disabilities. Although these public policy reforms seem to be moving in the right direction, nongovernmental solutions must also be considered. The lack of private capital and the nominal size of government budgets remain the most severe constraints on supplying and meeting the housing needs of people with disabilities. Given the current real estate market, it is a perfect time to reduce, if not eliminate, the waitlists throughout the country. Simple economic principles apply: (1) It costs less to house people with disabilities in the community than to institutionalize them; (2) there are defined waitlists of eligible tenants, so we know where the demand is; and (3) there is ample supply of housing inventory.

The 20th anniversary of the ADA is being celebrated by highlighting the great strides that have been made since its passage—as is appropriate. However, the occasion is also marked by awareness of how much remains to be accomplished. Financial institutions and CDFIs should embrace the disability market and provide it with leadership and solutions.

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References

Cornell University. 2007 *Disability status report*. Ithaca, NY: Cornell University.

Bjelland, M.J., W.A. Erickson, and C.G. Lee. November 8, 2008. *Disability statistics from the American Community Survey (ACS)*. Ithaca, NY: Cornell University.

Blimes, Linda. January 2007. *Soldiers returning from Iraq and Afghanistan: The long-term costs of providing veterans medical care and disability benefits*. Cambridge, MA: John F. Kennedy School of Government.

Bureau of Labor Statistics, *Labor force statistics from the Current Population Survey*,
<http://www.bls.gov/cps/cpsdisability.htm>.

Braddock, David. The Coleman Institute for Cognitive Disabilities.
https://www.cu.edu/ColemanInstitute/background_text.html.

Friedman, George. 2009. *The next 100 years*. New York: Knopf Doubleday Publishing.

National Alliance on Mental Illness. 2004 *Advocates' guide to housing and community development policy*. <http://www.namisc.org/Advocacy/2004/Summer/Section8Advocacy.htm>.

National Council on Disability. August 2003. *OLMSTEAD: Reclaiming institutionalized lives*.
<http://www.ncd.gov/newsroom/publications/2003/reclaimlives.htm>.

The U.S. Equal Employment Opportunity Commission. 2009. *Law and guidance*.
<http://www.eeoc.gov/policy/ada.html>.

U.S. Census Bureau. 2005. *Disability and American families: 2000*. Washington, DC: U.S. Census Bureau.
<http://www.census.gov/prod/2005pubs/censr-23.pdf>.

Understanding the Disability Housing Market

Sue Swenson

Changes in public policies are altering the U.S. market for housing and residential support services for people with disabilities. In the multi-billion-dollar publicly funded market for long-term services and support for people with developmental disabilities, which serves more than one million Americans, housing models are shifting away from institutions to consumer-driven choices that include community-based residences and living at home. Broader awareness of human rights and human potential are helping inform the expectations of the millions more who do not have access to public support, and many of these individuals are looking for opportunities to live more independently. But supply has not kept up with demand. Affordable, accessible, distributed housing is an increasingly critical need.¹ A challenge for the housing industry is the lack of detailed statistics on market demand.

Disability data sets generally measure epidemiology rather than market size or segments, and U.S. Census Bureau data do not report on the severity of disability (which would provide additional detail on housing needs) or eligibility for or participation in government programs. Sketches of market segments provide an alternative method to understanding the breadth of customers' preferences and needs. Such sketches can serve as a starting point for additional research that begins to identify detailed market segmentation of people with disabilities.

Background

In the United States and globally, housing for people with disabilities has begun to shift away from large institutional settings toward smaller community-based group homes and, more recently, toward individualized supports delivered wherever a person lives. Such services might include help with daily living tasks such as bathing, eating, dressing, and taking medication as well as help with exercise, positive behavior supports, and engaging in community interactions and friendships. This trend is strongest for people with intellectual and developmental disabilities (I/DD). Investments in research demonstrations and systems-change agendas have been small but consistent in the I/DD field for more than 40 years, so it is not surprising that innovation would originate here. The “homeward bound” movement has been driven by policy shifts and supported by mature technologies such as portable respirators and lifts, new technologies such as cell phones and web-based training and management systems, and emerging technologies such as environmental controls and personal coaching, communication, and monitoring systems.

¹ Distributed housing is housing that does not segregate people with disabilities in enclaves, gated communities, or institutional settings. Distributed housing also implies that housing is available in all kinds of neighborhoods and communities. Disability policy experts prefer that such housing is controlled by the resident and not tied to the services or supports received from an agency.

The trend toward individual support can be understood as the organizing force behind a new market. This trend is reinforced by new savings instruments and financial and tax planning policies and tools available to individuals and their families. The trend continues, but not without some bumps in the road. Below is a summary of some of the other forces at work in the marketplace:

- Few housing experts are deeply knowledgeable about disability issues, and few disability experts know a lot about housing policy.
- Information about housing support programs is not easily accessible to most people with disabilities or their families, who may lack community contacts, internet access, or information management skills.
- Family advocacy groups are often more familiar with how to raise funds for cures than they are with how to raise funds to provide information and referrals about community-based housing and supports.
- Many provider agencies know how to raise money for larger building projects but have not experimented with raising money for smaller housing models.
- Consumer-based budgets (versus facility-based budgets) and consumer control of support allocations are emerging models in most states, so management systems are not yet well-defined.
- The cost of individual support can be about half that of congregate care, but it has proven politically easier to cut individual supports during a budget crisis.
- Homeownership is complicated by the asset limits of public support programs such as Supplemental Security Income (SSI).
- In the nationwide push toward universal homeownership, not enough attention has been given to growing the low-income rental housing market; this is true in the disability market as well.
- Aging Baby Boomers will strain disability support systems, especially resources to pay for personal assistance jobs.

The market for people with disabilities who need affordable supportive housing in ordinary communities is large and growing. The current stock of safe, affordable, and accessible housing falls far short of the demand. Official state waiting lists indicate that nearly 100,000 Americans are waiting for residential supports, but estimates based on demography indicate the total may be closer to one million individuals.

Markets, Information, and Data

Unfortunately, there is a lack of useable data to support planning and marketing efforts. Disability data sets are seldom interoperable. Generally, they track the following measures:

1. Epidemiology and incidence. These data provide an overview of the number of people with disabilities, but do not provide information on how their functional limitations vary—necessary for understanding the housing needs of individuals.
2. Program spending. These are measures of state fiscal effort and are not intended to provide insight into whether individuals' housing and other needs are being met.
3. Functional limitations in activities of daily living (ADLs). U.S. Census statistics include supplemental reports on limitations in ADLs. Generally, these data do not show severity or multiplicity of limitations.
4. Program participation. The Social Security Administration manages large databases for the SSI program (for people who live in poverty with lifelong disabilities) and the Social Security Disability Income (SSDI) program (for adults who become disabled after beginning to work). The databases include names, birthdates, addresses, and disability category codes. They do not track severity of disability or participation in Medicaid Long-Term Services and Supports. Various other federal agencies track data that describe program participation, but the individual measures that underlie these reports cannot be linked to other data sets from other programs.

General market research databases have been collaboratively built by a variety of stakeholders, including the U.S. Census Bureau, consumer goods marketing companies, political interest groups, and financial and other services providers. These databases supply information on individuals' attitudes, lifestyles, values, and opinions, but typically have little information on how or where people with disabilities live. The information-rich databases can tell you which zip codes are likely to contain high numbers of people who hunt or fish, or people who travel internationally for leisure. However, they cannot tell you which zip codes contain a large population of underemployed people with disabilities, concentrations of young people with disabilities graduating from high school or college, or high numbers of families caring for or sheltering a significantly disabled family member into old age.

Without accurate, detailed, and easily accessible data, it is difficult to undertake the classic functions of marketing. Disability programs can identify their key constituencies but are unlikely to know much about the variation of preferences and needs within and among these groups. They might have strong connections to advocacy groups and individual advocates, but rarely do they have access to focus groups or descriptive data. Often, they build new services based not on consumer needs and wants, but instead on legislative and administrative agendas. Human services organizations seldom understand decision-making behaviors of key segments within their target populations, and they generally do not analyze the distribution channels that connect their services to their users. They seldom have data with which to understand how price relates to demand, or even how much demand exists. Because they lack the data that would help them describe key segments in the marketplace, they do not know how to reach potential users with new information.

Marketing Sketches

Marketing theory tells us that a market segment is a group of people who share a want, a need, and a way to pay. Typically, after completing a market segmentation study, a marketer might sketch out the motivations and desires of a “typical person” within that segment to help us understand them in human terms.

The following are some rudimentary market segment personae constructed with the intention of helping housing professionals better understand the variation in housing needs and wants of people with I/DD and other significant disabilities. The personifications here are fictitious and based on experience, not data. They should be used to stimulate interest in market research, not substitute for it. Taken together, the personae are not meant to be a complete representation of all people with disabilities in the United States—just examples of a few key segments of people with developmental disabilities who need housing.

Generation ADA

Andrew is a young advocate who was born on July 26, 1990, the day President G.H.W. Bush signed the Americans with Disabilities Act. Andrew has various significant learning disabilities and some emotional and behavioral difficulties that have emerged over time. He has a history of seizures. He has not yet graduated from high school in the medium-sized state university town where he grew up. However, when he turned 18 his school let him walk in the graduation with his friends, and now he attends the local college as part of his Individualized Education Plan. He was disabled enough to qualify for SSI at age 18. He works as a volunteer at the campus museum. He would like to move into an apartment, but he assumes he needs both a rent subsidy and some minimal supports in place to be able to do so. He is not sure whether he would be allowed to make accessibility changes to a rental apartment. Since he loses his keys a lot, some kind of fingerprint entry system would help. He has heard of a monitoring system that would log him into his house and report any seizure activity to 911. With this feature, maybe his mom would get off his back. His mother insisted he be put on a waiting list for Medicaid services, but the state says it will take 15 years to get to him. Andrew told his mom, “I will never use those services. I am disabled, but I want to work!” His class on civil rights history is currently studying fair housing laws. Andrew does not have a driver’s license. He would like to live within walking distance of the student union for now.

Getting By

Nancy, 44, was diagnosed with “mental retardation” when she was seven. She went to a special class that provided therapies and taught independent living skills in the city near her small town. Her mother is grateful that she has learned to follow instructions well. Nancy attends a sheltered workshop every day from 9:30 AM to 2:30 PM and attends a dance on the third Friday of every month, but receives no

additional supports. The workshop has contracts for recycling, shredding, and collating packets of documents for local non-profit board meetings. Participants are paid for helping with these tasks, based on their productivity, and are provided supervision and meals. Nancy brings home a check of around \$15.00 every two weeks. Her supervisors consider her unfocused and unproductive. She tells everyone she hates her job. Nancy's mother lives on her Social Security survivor benefits. She recently had knee surgery, and has trouble remembering to do her physical therapy. Nancy's SSI check is larger than most because she is a disabled adult child of a deceased father. If Nancy moves out, her mother cannot afford to maintain the house alone. Nancy's case manager at the workshop has signed her up for a Section 8 lottery for the last four years, with no luck.

Moving On

Justin is 32 years old and sometimes becomes very agitated at his job in the supermarket where he has worked for seven years. He is the produce manager, and has several teenagers reporting to him part-time as stockers. He was sent to special education when he was young, but he does not allow anyone to call him names anymore, not since he left the small town where he grew up. He does not claim any disability benefits. He graduated from a new vocational program after his foster family moved to the suburbs, and he excelled in every class. The program provided work opportunities during school hours and his quickly turned into a full-time job with health benefits. After a year or two, people at the supermarket seemed to forget Justin was "special ed." He loses his temper when one of the young kids at work calls the other one a "retard," and nobody knows what to do about it. He hunts and fishes to help provide for a family of four including his wife Stacy and their two children, ages three and five. He enjoys watching NASCAR races on TV and going to baseball games with his friend who drives, and he hopes to buy a townhouse for his family someday. He is insecure about making big decisions, but has no one to advise him.

24/7

Patrick is a 25-year-old with severe cerebral palsy who has a permanent tracheotomy and uses both a wheelchair and a walker. Patrick grew up with high expectations and with a strong awareness of civil rights. He lives at home with his parents. His mom is a nurse and his dad teaches English at the local suburban high school. Family support programs helped the family construct a first-floor bedroom and bath for Patrick 19 years ago. The accessible space provides room for a hospital bed and other equipment, and a place for overnight staff to work on health records. The bathroom has a ceiling-mounted lift, making the tub and shower useable. Patrick has easy access to the family living room and kitchen. He receives 120 hours per week of individual support including overnight nursing. His parents fill in the rest of the time. He is studying web design at a local community college and has a budding relationship with a young woman he met there. His girlfriend has disabilities, too. He would like to move out of his parents' home—soon!—and he would like to minimize his reliance on staff by using more

assistive technology at home. His state does not yet allow substitution of electronic monitoring for staff oversight. He has looked at low-income apartments, but they do not offer enough room or access for him to be comfortable or safe, especially in the bathroom. He also needs to live near public transportation.

Gone, Baby, Gone

Duke dropped out of "Sobriety High," an alternative high school for youths who have substance abuse issues. He is 16 years old. The school thinks his family moved away, but the fact is his foster family was going to kick him out again so he just left. He is not aware that the family was receiving SSI disability benefits on his behalf. He is living temporarily in a garage behind a friend's house, and uses any drugs he can find to help kill the boredom. Duke tried to apply for a sales clerk job at a big retail chain, but he does not read well enough to fill out the job application. He reads at a third-grade level. Duke is not worried about getting into trouble with the law. He has been in juvenile detention twice already and prefers it to foster care. At least they have pool tables and video games in juvenile detention—and nobody hassles him or calls him stupid there.

Over the Hill

Earnest is a gentleman of 67, but he seems older than that. For him, lack of coordination caused lack of activity and general muscle weakness. Earnest walks with a significant limp and has severe osteoporosis. As a young man, he was diagnosed as having intellectual disabilities; his sister thinks he would now be diagnosed as having autism. He lives with his mother, who is 92, in the same apartment building they have always lived in on the South Side of the Metro area. Earnest's mother is still spry, but worries that she might die before her son. Then what will happen to him? She and her husband turned down an institutional placement 60 years ago. Earnest is a fixture at the local library, where he volunteers every Tuesday and Thursday at 10:00 AM. He also helps several "old people" in his building by returning library books for them (he reminds them when they are due) and by assisting them with their checkbooks. Earnest is good at basic math and is also a whiz at fixing dripping faucets. He keeps the apartment spic-and-span and makes his bed and his Mom's bed every day. Earnest does not have a checking account of his own. Earnest does not know how to cook. He says, "Fire makes me nervous." His cousin, who is an insurance salesman, keeps trying to set up an irrevocable trust for Earnest. His mother thinks the cousin is just a hustler, so she won't discuss it. Earnest's mother secretly hopes that after her death her daughter will move Earnest into her home, but there are no such plans in place. Earnest carries his sister's cell phone number in his wallet in case something bad happens.

The Least of These

Violet's mother often refers to her as being among the most severely retarded people in the State. Violet is 52 years old and has lived in a large state-run institution since she was 13, which her mother

says is proof of how "retarded" she is. Violet's mother is proud of her own advocacy, which has landed Violet in Happy Acres, the "best" institution in the state, with an annual per-person cost over \$250,000. The State is making noises about closing its public institutions. Since the dog died, Violet is no longer willing to visit her parents' home, a beautiful country estate. Violet's mother has never seen a community home that she feels would be supportive enough for Violet; she thinks the State has under-resourced its community options. Violet has a very large trust fund that provides for incidental expenses. It appears that the trust could be used for housing, but it may not be used for long-term support costs.

Baby Steps

Angelina is a cute 3 1/2-year-old girl whose mother always dresses her like a little angel. She is the youngest of three children born to a very wealthy family in the leafy suburbs of a large American city. Angelina has been identified as having autism. Her family has heard about a proposed tax sheltered savings account called an ABLE account. It would allow them to save for Angelina's future housing needs in the same way families can save for college costs. However, Congress has not yet authorized such savings plans. Angelina's mother has quit her job to manage the plethora of therapies and interventions that Angelina is scheduled to receive. It is unclear what the family's financial future will be, and it is unclear what the extent of Angelina's disabilities will be as she grows up. Though she currently has some balance and gross motor problems, she seems eager to run away at any opportunity. The family is struggling to try to find ways to adapt their home so that it will be more supportive of Angelina. In desperation, they have installed bolt-type locks on the outside of her bedroom door and are planning to build a tall fence around their yard, but they cannot believe that these are the best options. Support from the Early Intervention Team does not include financial advice or advice about home modifications.

Conclusion

These sketches provide some examples of the ways in which the preferences, needs, and finances of people with developmental disabilities can vary. My hope is that advocates, marketers, policymakers, housing experts, and financial leaders will find some material here for thinking about how to segment markets of people with disabilities to help them reach different groups.

People who live in the same kinds of neighborhoods tend to have similar needs, wants, and aspirations, but it is clear that the presence and extent of a disability can change those underlying needs and wants significantly. Disability may undermine a family's ability to pay privately, but not all people with disabilities are poor. Eligibility for public programs may provide funding opportunities, but at the same time, it may constrain choice. Modern individualized budgets create options and a real market for services and supports where there was no individual choice in the past.

Non-profits are traditionally less experienced than for-profit business with marketing and market research, but these contribute to the focus and effectiveness of programs. While the specific market

data may not exist, housing experts can use traditional approaches to creating market segmentations with what information is available. Every U.S. state and territory has Developmental Disability Act programs and state and local Independent Living Centers. These federally funded programs study and report on the needs of persons with disabilities. Organizations can make progress through exploratory processes such as focus groups and through structured studies of the markets they wish to serve. Low-cost market research may also be available through local business schools and universities.

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Throughout these discussions, we explore the link between disability and poverty, including the complex interactions among public support programs, income, asset accumulation, and tax policies.

Demographic Data

There are over 200 disability programs across 23 federal agencies, costing over \$300 billion a year. Yet, there is a distinct absence of disability data from briefs on poverty and health care reform, suggesting that disability status is given less weight in policymaking than other demographic information such as race and ethnicity, age, family status, nativity, and work experience (Fremstad, 2009; Hartnett and Morris, 2005; Ball, Morris, Hartnett, and Blanck, 2006). There has also been little research to date on the link between disability and poverty (U.S. Government Accountability Office, 2005; Hartnett and Morris, 2005). However, strides have been made in the collection and reporting of data on the economic condition of people with disabilities. Here we provide highlights of these new data.

General

There are 54 million Americans with disabilities; that translates to one out of every five civilian, non-institutionalized persons (Cornell University, *Disability Statistics*). Of these, 35 million have a disability that significantly interferes with everyday activities.

Disability Type

Cornell University provides the following estimates across disability type (reported for individuals over the age of five): Sensory, 11.7 million individuals; physical, 25.7 million; mental, 15.9 million; self-care, 8.3 million; go-outside the home, 12.4 million; employment, 13.6 million.

Disability Prevalence

Cornell University reports the following prevalence of disabilities across race and ethnicity: Whites, 12.6 percent; Black/African Americans, 17.0 percent; Asians, 6.3 percent; Native Americans, 22.5 percent; Hispanic/Latino, 10.7 percent; other, 11.7 percent.

Employment

There are 22 million working-age individuals (between the ages of 16 and 64) with disabilities. Of these, 7.6 million are working and five million file a tax return (Internal Revenue Service, 2007). The U.S. Department of Labor reported that in June 2010, 15.6 percent of people with disabilities were unemployed compared to 9.6 percent of people with no disability (U.S. Bureau of Labor Statistics). The employment-to-population ratio for people with disabilities was 28.5 percent compared to 70.3 percent for people with no disability.

Median Income

For employed individuals between the ages of 21 and 64, the median income is \$17,150 for those with a disability and \$24,160 for those with no disability (U.S. Census Bureau, 2005). For the 20.8 million families who have a member with a disability, median income is \$39,155, compared to \$50,046 for the 51.3 million families who do not have a member with a disability. The following summarizes the differences in sources of income for families who have a member with a disability versus families who do not: wages and salaries, 73.1 versus 89.3 percent of earnings; self-employment, 11.1 versus 14.8 percent; Social Security, 42.8 versus 14.2 percent; SSI, 11.7 versus 0.9 percent; public assistance other than Social Security and SSI, 6.5 versus 2.7 percent.

Poverty

Disability and poverty are highly correlated; over half of all working-age adults who experience poverty also report a disability (Fremstad, 2009). The IRS reports that 51 percent of taxpayers with disabilities have Adjusted Gross Incomes of less than \$21,000 a year (Internal Revenue Service, 2007).

She and Livermore (2009) report that people with disabilities experience poverty two to five times more often than people with no disability and that 65 percent of people experiencing long-term poverty (longer than a year) have a disability.

Access to Free Tax Preparation and the EITC

State-by-state analysis by the IRS shows that among low-income filers (those with incomes less than \$38,348), taxpayers with disabilities access free tax preparation services at a lower rate (1.6 percent) than taxpayers with no disability (3.5 percent). This suggests that more can be done to ensure equal access to these services (Hartnett, ongoing). The IRS also estimates that \$1 billion in EITC refunds go unclaimed by taxpayers with disabilities annually.

Social Security

There are an estimated 11 million people with disabilities who receive some form of Social Security benefits (Social Security Administration, 2007a). As much as 40-50 percent of the 6 million people receiving SSI are considered *unbanked*, having no checking or savings account. Persons participating in income maintenance programs such as SSI and Social Security Disability Insurance (SSDI) and who have access to “work incentive” programs (e.g., the Plan to Achieve Self Support/PASS and the Property Essential to Self Support/PESS) demonstrate low rates of participation in such savings vehicles (Social

Security Administration, 2007b). Moreover, only 23 percent of Medicaid Buy-In participants who qualify for SSDI use any one of the work incentives available to them (Mathematica Policy Research, 2007).¹

Market Trends

Marketing research indicates that people with disabilities are living longer, living more independently, and taking on more responsibility for the management of their budgets and resources than ever before (Solutions Marketing Group, *Disability Facts*). People with disabilities want information on how to save, where to save, how to plan for the future, how to manage debt and credit, how to buy a home, how to optimize available tax credits, how to use federal work incentives, where to bank, how to invest, and where to get free tax-preparation assistance. Fully 48 percent of people with disabilities report that the Internet has significantly improved the quality of their lives compared to 27 percent of people without disabilities. However, 41 percent of people with disabilities do not use a computer at home compared to 24 percent of people with no disability (Hartnett, ongoing).

Savings and Investment Behavior

IRS analysis shows that 37 percent of people with disabilities use financial institutions for savings and investments compared to 51 percent of people with no disability; 30 percent of people with disabilities do not invest compared to 12 percent of people with no disability; 23 percent of people with disabilities rely on family, friends, and neighbors to help them through a financial emergency compared to 40 percent of people with no disability; 18 percent of people with disabilities use online banking compared to 37 percent with of people with no disability; and 16 percent of people with disabilities use financial advisors compared to 29 percent of people with no disability (Internal Revenue Service, 2007).

Real Economic Impact (REI) Tour

The REI Tour is a national initiative and partnership with the IRS VITA program designed to deliver free tax preparation and filing assistance along with other asset-building strategies to low-income persons with disabilities. The REI Tour is designed to increase the number of tax filers with disabilities and their use of tax credits and deductions; build local partnerships among persons with disabilities and their families, disability- and community-based organizations, and companies that sponsor the Tour; and promote measurable economic growth in participating cities.

The REI Tour provides mini-grants and technical assistance to community-based coalitions providing free tax preparation services to expand their disability capacity. REI Tour cities have used these resources to make their tax sites accessible, provide education to their volunteers about disability sensitivity, and hold trainings on the use of technology—such as Video Relay Services for assisting deaf

¹ Medicaid Buy-In programs enable people to save income from wages while retaining access to essential health coverage.

taxpayers. The REI Tour also hosts an annual national conference and provides stipends for lead partners to convene and share best practices. The Tour has been sponsored by private sector organizations including Bank of America, AT&T, Walmart, Acorda Therapeutics, Inc., 54Freedom, and Darden Restaurants Foundation.

Since the start of the REI Tour in 2005, local partners have provided free tax-filing assistance to 332,903 taxpayers with disabilities (see Table 1).² The tax returns to these taxpayers amounted to \$312.3 million. The REI Tour grew from serving 11 cities in 2005 to 100 cities in 2010 and is in all 50 states. In its short history the REI Tour has saved taxpayers with disabilities over \$138.4 million in paid preparer fees.

Table 1

REI Tour Partner Outcomes

Year	Cities	Local Partners	Returns Prepared	Percent Increase	Refunds Received (\$ millions)	Savings in Tax Prep Fees (\$ millions)
2005	11	----	7,600		\$6.8	\$1.5
2006	30	200	17,223	127%	\$15.3	\$3.4
2007	54	355	36,275	111%	\$32.6	\$7.2
2008	62	555	90,653	150%	\$81.0	\$18.1
2009	84	634	181,152	100%	\$176.6	\$36.2
2010	100	700	360,499	99%	\$351.6	\$72.0
TOTAL	100	700	693,402		\$663.8	\$138.4

For the first four years, REI Tour partners hand-collected data on the number of taxpayers with disabilities coming to the VITA sites. Starting in 2009, the IRS TaxWise software has included a question about taxpayer disability status. VITA sites are using the knowledge gained as part of the REI Tour to develop outreach and education efforts, enlist new funding sources, and develop universal tax preparation models that can better serve taxpayers with disabilities. The VITA site data show that about 13 percent of taxpayers at the sites either report a disability or report being the head of household with a person with a disability. About 51 percent of taxpayers with disabilities surveyed by IRS Wage and Investment Research were found to have an average adjusted gross income of \$21,000 or less, linking disability to the profile of low-income tax filers. VITA site partners realize that many of their low-income taxpayers are indeed taxpayers with disabilities from diverse backgrounds. In Detroit, MI, 31.0 percent of VITA taxpayers identify themselves as having a disability; in Rochester, NY, 18.1 percent; in Wichita, KS, 28 percent; in Flint, MI, 34 percent (Hartnett, ongoing).

² For a full report on the outcomes of REI Tour partners, visit <http://www.reitour.org/docs/annualreports/2009REIReport.pdf>.

In 2009 and 2010, the REI Tour, in partnership with DeafTax.com—a tax preparation service for the Deaf provided by Schwarz Financial Services—and 14 cities implemented a pilot project aimed at promoting access to free tax assistance for deaf taxpayers. The pilot used state-of-the-art Video Relay Service (VRS) technology to connect deaf tax preparers using American Sign Language (ASL) interpretation to bring real-time, remote, free tax preparation to deaf taxpayers who qualified for the EITC. A survey of the pilot participants indicates that preferences of deaf taxpayers using free tax assistance services include: VRS technology, an ASL interpreter, lip reading, a teletypewriter (TTY) for communicating, and written communication.³

New Hampshire Field Research

The community economic development sector has demonstrated transformational outcomes for people and communities historically overlooked by traditional forms of economic development (Dubb, 2005; Simon, 2001). However, until recently, the disability market has been largely overlooked by the community development field. Much of this has to do with the perception that public policy limits the degree to which people with disabilities can earn money and save money, calling into question the degree to which the disability market is viable. But recent changes in public policy make it easier than ever before for adults with significant disabilities to accumulate savings. For example, 42 states have Medicaid Buy-In programs. SSI and SSDI beneficiaries now have access to a variety of work incentives within the programs to facilitate savings and financial self-sufficiency. Moreover, opportunities are available within subsidized housing programs, including, but not limited to, Family Self Sufficiency Escrow options and Section 8 Voucher Assisted Mortgages. Finally, Individual Development Accounts are offered through many CDFIs in partnerships with banks, some of which use lending instruments such as Assistive Technology Loan Products.

Although policy barriers still exist, and greater investments are needed, the most critical obstacle for community development engagement of this market is that many practitioners do not understand how disability programs interact and how they can be effectively combined or “braided” (individually and systemically) to achieve larger gains in economic self-sufficiency of persons with disabilities and local communities—desirable outcomes for both fields of practice.

Historically, people with disabilities have used disability-specific human-service agencies as a primary source of information and service provision. While this link is critical, these agencies tend to limit their involvement in financial-related matters to Social Security and Medicaid-related benefit programs. Given the low rates of participation among SSI and SSDI beneficiaries in work incentive programs such as the PASS, PESS, and Impairment Related Work Expenses (IRWE) programs, expanding access to a service mix from the community development field is a worthy endeavor. Such linkages can help individuals with disabilities leverage support and services from both sectors, as well as help provide community development organizations with the knowledge necessary to avoid the unintended

³ For a full report on the pilot project, visit <http://www.reitour.org/docs/deaftax09.pdf>.

consequence of disqualifying individuals with disabilities from income support or health insurance programs.

Recognizing the gap between the activities of human-service agencies and community development organizations, Southern New Hampshire University undertook the Financial Education and Volunteer Income Tax Assistance Study to explore the application of a comprehensive financial coaching model to the financial security and asset holdings of individuals with disabilities. The summary of the study below highlights some of the outcomes possible through interagency coordination.

Methodology

This study was exploratory, non-experimental, and used multiple methods to examine the impact of integrating financial counseling efforts—including VITA counseling, credit counseling, household budgeting assistance, and work incentives counseling—on the financial stability and savings accumulation of participants with disabilities. Researchers also connected participants to asset-building programs such as IDAs and Financial Self Sufficiency programs.⁴ As early-stage research, the project recruited a purposeful sample of adults with disabilities between the ages of 25-65 who had evidence of earned income during the tax year and who accessed services from participating community partner agencies including the New Hampshire Bureau of Vocational Rehabilitation, a local community mental health center, or another local area agency. Community partners disseminated recruitment flyers and hosted informational forums to educate their clients about the opportunity to participate in the research.

Due to the non-experimental nature of the study design, the characteristics of the study sample are not representative of the disability community. Study results are not generalizable, and at best only suggest a possible correlation between the study protocol and the outcomes achieved by study participants.⁵

Study Participants

A total of 46 participants consented to take part in the research study. Data from 39 of these individuals are included here⁶. At the time of intake, the average age of study participants was 42. Twenty

⁴ Financial Self Sufficiency (FSS) Accounts are available through housing authorities for individuals who qualify for Section 8 Housing. FSS Accounts allow participants to escrow a percentage of their earnings that would otherwise increase their rental contribution. These earnings can then be used to fund goods and services that help promote the participant's financial independence.

⁵ A second generation random-sample study following the treatment protocol discussed here—the REAL Opportunity Study—is being implemented in the states of New Hampshire and Wisconsin in partnership with state Divisions of Vocational Rehabilitation (DVR). The study is led by the University of New Hampshire's Institute on Disability in partnership with the Burton Blatt Institute at Syracuse University with funding from the National Institute on Disability for Rehabilitation Research. The project is investigating whether comprehensive financial coaching leads to significant differences in asset holdings and financial well-being of DVR participants compared to the outcomes attained by the control group that receives services as usual. Study results will be available in 2012.

⁶ Thirty-nine of the 46 participants who enrolled in the project completed the study.

participants reported mental illness as their primary disability, eight reported “other disabilities,” five reported a physical disability, four reported a developmental disability, and two reported speech disabilities. Over half of all participants had never been married, lived alone, and had at least a high school diploma. Eleven participants had dependent children. Thirty-one participants worked at least part-time with a mean wage of \$8.85 per hour.

For analysis purposes, participants were stratified into sub-groups to explore any possible correlation between their stated reasons for joining the project and the outcomes achieved. Participants were divided into five categories based on their responses to questions about their financial goals: the “Build My Financial Future” group (n=10) were those who expressed strong motivation to improve their long-term financial futures; the “Control Spending” group (n=7) were those who expressed the need to reduce their expenses in order to live within their means; the “On My Own” group (n=4) were those who expressed the desire to have more financial independence from significant others (e.g. partners, parents, and Representative Payees); the “Learn More About It” group (n=10) were those who wanted more information about available resources but did not express specific financial goals; and the “Financial Crisis” group (n=8) were those who conveyed they were under financial stress and in urgent need of financial counseling.

Findings and Observations

Financial Services Market Participation

Thirty-three participants (85 percent) had bank accounts at the time of project enrollment. Fourteen had only a checking account, four had only a savings account, and 15 had both checking and savings accounts. Six participants were unbanked. The Build My Financial Future group had the largest number of banked participants.

Most participants with established lines of credit belonged to either the Control Spending group or the Financial Crisis group. Four participants held mortgages, three participants had home equity lines of credit, 11 participants had auto loans, and 14 participants had at least one credit card (some participants reported more than one line of credit). In addition, three participants had student loan debt, but this status was equally distributed among the Build My Financial Future group, the Control Spending group, and the On My Own group.

At the start of the study, seven participants established new deposit-only accounts as part of their enrollment in IDA programs. By the end of the research, two study participants used savings from their IDA programs to purchase new home mortgages with total housing costs not exceeding 30 percent of their household income. One study participant qualified for an affordable car loan (which was consistent with her financial goals) as a result of correcting flaws on her credit report and increasing her earned income. One participant paid down the principal on her mortgage and home equity line of credit as a result of the untimely death of her spouse and subsequent life insurance payments. Several participants

increased their use of financial services; the Build My Future group increased the use of these services more than any other group.

Savings Accumulation

The percentage change in savings varied among the groups (see Table 2). Post tests indicated that the Build My Future group increased their savings by more than 28 percent by making use of IDAs and the EITC. The percent change in savings is inflated for the Financial Crisis group because of the life insurance settlement received by one member. Aside from bank savings accounts, other savings vehicles utilized by study participants included retirement savings (n=4), Special Needs Trusts (n=3), money held by family (n=3), savings at home (n=2), stocks and bonds (n=1), certificates of deposit (n=2), Employability Accounts (n=1), FSS Accounts (n=1), and Plans for Achieving Self Support (PASS) (n=1).⁷

Table 2
Change in Savings Accumulation

Type of Participant	Total Savings Intake	Total Savings at Follow-up	Percentage Change
Build My Future	\$795.31	\$1,015.14	27.6%
Control Spending	\$5,671.41	\$5,529.50	-2.5%
On My Own	\$517.75	\$641.50	23.9%
Learn More About It	\$656.20	\$493.33	-24.8%
Financial Crisis	\$3,786.13	\$8,775.63	131.8%
Total	\$2,219.87	\$3,257.82	46.8%

Debt Reduction

All groups reduced their debt within the first six months of participation (see Table 3). The percentage of debt reduction ranged from 27 percent to 73 percent. The three groups with the largest percentage reduction in debt were the Control Spending group (73 percent reduction), the Financial Crisis group (60 percent reduction), and the Build My Future group (58 percent reduction). After 12 months of enrollment in the study, all groups continued to reduce their debt with the exception of the Build My Future group. The behavior of this group was explained by significant events experienced by three of the ten participants in the group: One participant acquired an affordable car loan consistent with her financial goals; one participant lost her job and increased her credit card debt while unemployed; a third

⁷ Employability Accounts are savings vehicles in New Hampshire's Medicaid for Employed Adults with Disabilities (MEAD) program, the state's Medicaid Buy-In program. MEAD maintains health care for workers with disabilities by incentivizing real income gains and by excluding resources accumulated as a result of employment that would otherwise disqualify participants from health insurance coverage available from the Medicaid program.

participant was exploited by a highly influential family member who convinced her to open an account with a predatory lender. The account was later paid off in regular installments.

Table 3

Debt Reduction

Type of Participant	Total Debt Intake	Total Debt at Follow-up	Percentage Change
Build My Future	\$3,541.30	\$1,502.00	-57.6%
Control Spending	\$97,507.71	\$26,622.51	-72.7%
On My Own	\$1,418.25	\$1,037.50	-26.9%
Learn More About It	\$1,418.20	\$955.56	-32.6%
Financial Crisis	\$49,581.25	\$19,877.42	-59.9%
Total	\$29,089.03	\$9,365.52	-67.8%

Asset-Building Program Participation

All seven IDA participants were members of the Build My Future group. Three of the IDA participants pursued post-secondary education using savings from their IDAs, two participants pursued home ownership, and two participants pursued business development. All but two of the IDA participants graduated or are anticipated to graduate from the IDA program. Two participants saving for post-secondary education were terminated from the IDA program because they were unable to secure employment for a lengthy period of time.

Those who have graduated from the IDA program, or otherwise maximized their savings contribution, have done so through *resource braiding*, the practice of leveraging multiple programs for achieving greater financial gains. For example, one participant leveraged the EITC program, a PASS plan, the IDA program, and the Ticket to Work program to buy a used car with cash and pay for tuition and books for graduate school. He is currently working in his preferred occupation, completing his graduate work, and in the process of building a positive credit history; all these steps are moving him toward his long-term goal of homeownership. Another participant used her IDA savings to cover insurance payments on the accessible van she uses to commute to her teaching and consulting appointments. A married couple increased their earned income and outperformed all other IDA participants in terms of their savings rates. They qualified for a Section 8 Home Ownership Voucher and a loan from the U.S. Department of Agriculture to purchase their condo within walking distance of the local supermarket and their places of employment.

Services Utilized

An index was created to determine whether there is a correlation between the utilization of the four core services (work incentive counseling, VITA services, consumer credit counseling/budgeting, and asset building programs) and the outcomes attained (percent change in savings, debt reduction) (see Table 4). The participants who accessed all four core services were ranked as “high” users of services. Those who accessed two or three of the core services were ranked as “medium” users. Those who accessed one or no service were ranked as “low” users. The Build My Future group utilized services more than any other group. This group’s large increase in savings and debt reduction suggests a correlation between services utilized and outcomes achieved. Also, participants who used consumer credit counseling services were among those who reduced their debt most. It appears that there may be value in matching a narrow set of services to participants’ goals.

Table 4
Services Utilized

		Services Utilized			total
Type of Participant		High	Medium	Low	
Build Future	count	1	7	2	10
	% within	10.0%	70.0%	20.0%	100.0%
Control Spending	count	0	3	4	7
	% within	0.0%	42.9%	57.1%	100.0%
On My Own	count	0	3	1	4
	% within	0.0%	75.0%	25.0%	100.0%
Learn More	count	0	2	8	10
	% within	0.0%	20.0%	80.0%	100.0%
Crisis	count	0	3	5	8
	% within	0.0%	37.5%	62.5%	100.0%
Total	count	1	18	20	39
	% within	2.6%	46.2%	51.3%	100.0%

Implications

The financial coaching model used in this study linked community development and disability service resources in an attempt to improve the financial security and asset holdings of participants. The study provided insight into participants’ use of financial services as well as their practice of resource braiding. The participant outcomes also suggest that connecting low-income individuals with disabilities to financial counseling and asset-building resources may help them build assets and reduce debt. The findings of this study are not generalizable to a wider population given the non-random nature of the

Disability-Inclusive Asset Building: New Strategies for Achieving Real Economic Impact for Americans with Disabilities

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This paper reflects the leadership of thousands of people across the United States committed to building a better economic future for Americans with disabilities. In 2000, the National Disability Institute (NDI) sparked a national dialogue when it invited community development organizations, disability service organizations, universities, and federal agencies to join a monthly meeting to discuss how gains in the asset-building field could be extended to people with disabilities. Washington, DC-based participants gathered in the basement of the National Cooperative Bank as others called in from around the country for the brown-bag luncheon series titled "With Equity and Assets for All" (WEAFA).

Some of the first questions raised in these monthly meetings related to asset limits. What happens to a working person's Supplemental Security Income (SSI) or Medicaid benefits if they claim the Earned Income Tax Credit (EITC) or participate in a matched savings program like an Individual Development Account (IDA)? Some wanted to know how asset-building products or tax reform might help people with disabilities working at well-paying jobs and not on public benefits defray the high out-of-pocket expenses associated with working (e.g. paying for a powered chair or hiring a personal assistant). Other questions surfaced around the accessibility of and support provided by local community economic development resources and private-sector financial services. Do Volunteer Income Tax Assistance (VITA) sites or IDA programs reach out to the customer with a disability? How well are financial institutions reaching these customers? Do investments in this underserved market qualify for Community Reinvestment Act (CRA) credit? After a year of meetings, it was clear that there were still many unknowns. It was also obvious that no one had asked people with disabilities about their tax and financial service needs or about how they save or manage their finances. There were no well-developed ideas about what products, services, or tax policies could help them increase their economic self-sufficiency.

The luncheon discussions prompted participants to begin research on asset accumulation for people with disabilities and to look for ways to leverage existing community development resources and adapt existing asset building programs to meet the needs of this group. This paper describes some of these efforts and their results. We begin by providing new demographic data related to the economic condition of people with disabilities. Next, we describe the partnership between NDI's Real Economic Impact (REI) Tour and the VITA program of the Internal Revenue Service (IRS) aimed at providing asset-building strategies and free tax preparation and filing assistance to people with disabilities. We also describe exploratory research by Southern New Hampshire University examining the effect of asset-building products and services on the market participation of low-income individuals with disabilities.

sampling method and the small sample size. However, the results do suggest that there are untapped resources for low-income people with disabilities within existing community-based organizations, and that tailored financial counseling can help leverage these resources.

The services utilized in the study are available in most local communities. Thus, there is potential for developing and replicating the comprehensive financial coaching model. There is also the potential to pair the work done by community development and disability service organizations with the resources of the REI Tour partnerships. Investments in all of these community-based organizations can further strengthen outcomes.

Improving the economic and social mobility of persons with disabilities is the cornerstone of the contemporary disability framework. Poverty reduction, economic security, and asset-building strategies are natural extensions of this aim. We strongly recommend further research into how community-based programs can promote the financial well-being and social participation of this neglected audience. Such research can provide insight into how to strengthen these programs and inform community development stakeholders of investment opportunities.

Conclusion

The resources and knowledge housed in community development organizations, including asset-development programs, hold great potential for benefiting low-income individuals with disabilities. The REI Tour and the Financial Education and Volunteer Income Tax Assistance Study provide examples of partnerships between community-development organizations and disability service organizations that serve to enhance the economic and social well-being of low-income taxpayers with disabilities. We recommend the following next steps for research and program and policy development:

1. Study access issues limiting the economic advancement of people with disabilities. For example, the REI Tour DeafTax VITA Pilot identified the importance of using technology to provide free tax filing services to deaf taxpayers. Additional research can identify how to improve access to free tax assistance and other asset-building programs for the Blind.
2. Include a disability variable in public and private data collection to improve knowledge of the needs and preferences of the disability market. For example, there are few data on tax and finance preferences of taxpayers with disabilities who are not eligible for EITC.
3. Develop a better understanding of the financial service needs of the disability market. Survey the accessibility of financial services to disability population groups (i.e., visually impaired, deaf, intellectual, mobility). Conduct additional research on the banking, credit, and asset development practices of low-income working persons with disabilities to identify barriers they may face in accessing the financial mainstream.
4. Increase the capacity of financial institutions to customize services and products to meet the needs of the disability market through the use of product development and training resources. In addition, research the role of technology in connecting customers with

disabilities to banking services.

5. Promote public policy that addresses the asset-building needs of the disability market, including raising asset limits related to public benefits. Promote awareness of how serving the financial needs of people with disabilities may constitute eligibility for CRA credit.

The first generation of research and program implementation described above has shown that the disability market segment is large and viable. The REI Tour data portray a typical EITC-eligible taxpayer with a disability as unbanked or underbanked, lacking in major assets such as a home or pension, and with limited opportunity for economic mobility. In the New Hampshire study, taxpayers with significant disabilities were found to benefit from comprehensive, targeted financial coaching when these services were used in combination with other community development and public programs. As we move forward in these tough economic times, we believe that this work conveys a message of hope and ideas for advancing economic empowerment for Americans with disabilities.

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References

Andrews, Kristen, Bob Weathers and Su Liu. December 2007. *How Do Medicaid Buy-In Participants Who Collect Social Security Disability Insurance Benefits Use SSA Work Incentive Programs?* Mathematica Policy Research. Working with A Disability. Number 7.

Ball, Phoebe, Michael Morris, Johnette Hartnett, and Peter Blanck. 2006. Breaking the cycle of poverty: Asset accumulation by people with disabilities. *Disability Studies Quarterly* 26, no.1 (Winter), <http://www.dsqsds.org/article/view/652/829>.

Cornell University. *Disability statistics: Online resource for U.S. disability statistics*. <http://www.ilr.cornell.edu/edi/disabilitystatistics/index.cfm?n=1>.

Dubb, Steve, ed. 2005. *Building wealth: The new asset-based approach to solving social and economic problems*. Queenstown, MD: The Aspen Institute.

Fremstad, Shawn. 2009. *Half in ten: Why taking disability into account is essential to reducing income poverty and expanding economic inclusion*. Washington, DC: Center for Economic and Policy Research. <http://www.cepr.net/index.php/publications/reports/half-in-ten/>.

Hartnett, Johnette. 2006. *Educating democracy: Tax and financial service needs of working Americans with disabilities*. Washington, DC: National Disability Institute. <http://www.realeconomicimpact.org/>.

———. Ongoing. Data analysis for the Internal Revenue Service Stakeholder Partnerships, Education, and Communication Disability Initiative.

Hartnett, Johnette and Michael Morris. 2005. *The state of 21st century long-term services and supports: Financing and systems reform for Americans with disabilities*. Washington, DC: National Council on Disability.

Hartnett, Johnette, Michael Morris, Daniel Apfel, et al. 2008. *Building a better economic future: A progress report for individuals with disabilities and their families in America*. Manchester, NH: School of Community Economic Development, Southern New Hampshire University. <http://www.realeconomicimpact.org/>.

Internal Revenue Service. 2007. *Characteristics of disabled taxpayers ages 18-59: Study of filing patterns and preferences for receiving tax information and services*. Prepared for the Internal Revenue Service Stakeholder Partnerships, Education, and Communication Disability Initiative by the Wage and Investment Research Group 4. Washington, DC: Internal Revenue Service. <http://www.irs.gov/pub/irs-pdf/p4640.pdf>.

Mendelsohn, Steven. 2006. Role of the tax code in asset development for people with disabilities. *Disability Studies Quarterly* 26, no.1 (Winter), <http://www.dsqsds.org/article/view/653/830>.

National Disability Institute. 2006. *Focus groups with taxpayers with disabilities*. Prepared for the Internal Revenue Service Stakeholder Partnerships, Education, and Communication Disability Initiative by the Wage and Investment Research Group 4. Washington, DC: National Disability Institute. <http://www.realeconomicimpact.org/>.

Schmeling, James, Helen Scharz, Michael Morris, and Peter Blanck. 2006. Tax credits and asset accumulation: Findings from the 2004 N.O.D./Harris Survey of Americans with Disabilities. *Disability Studies Quarterly* 26, no.1 (Winter), <http://www.dsqsds.org/article/view/654/831>.

She, Peiyun and Gina Livermore. 2006. *Long-term poverty and disability among working-age adults*, Research and Training Center on Employment Policy for Persons with Disabilities Research Brief. Ithaca, NY: Cornell University. <http://digitalcommons.ilr.cornell.edu/>.

Simon, William. 2001. *The community economic development movement: Law, business, and the new social policy*. Durham, NC: Duke University Press.

Social Security Administration Office of Policy, *Fast facts and figures about Social Security, 2007*, http://www.socialsecurity.gov/policy/docs/chartbooks/fast_facts/2007/fast_facts07.html#oasdi.

Social Security Administration. 2007a. *Annual report of the Supplemental Security Income Program*. Washington, DC: Social Security Administration. <http://www.ssa.gov/OACT/ssir/SSI07/ssi2007.pdf>.

———. 2007b. *Voices for change: beneficiaries paving the way to work: A roadmap to program improvement*. Prepared for the 2007 Beneficiary Summit by the The Ticket to Work and Work Incentives Advisory Panel. <http://www.socialsecurity.gov/work/panel/summit/summitmain-1.htm>.

Solutions Marketing Group. *Disability facts*, <http://disability-marketing.com/facts/>.

U.S. Census Bureau. 2006. *Americans with disabilities: 2002*. Washington, DC: U.S. Census Bureau. <https://www.census.gov/hhes/www/disability/sipp/disable02.html>.

———. 2008. *Current Population Survey, annual social and economic supplement*. <http://www.census.gov/cps/>.

U.S. Census Bureau. 2005. *Disability and American families: 2000*. Washington, DC: U.S. Census Bureau. <http://www.census.gov/prod/2005pubs/censr-23.pdf>.

———. 2008. *Facts for features: Anniversary of Americans with Disabilities Act*. Washington, DC: U.S. Census Bureau Public Information Office.

U.S. Department of Labor, Bureau of Labor Statistics, *Labor force statistics from the Current Population Survey*, <http://www.bls.gov/cps/cpsdisability.htm>.

U.S. Government Accountability Office. 2005. *Federal disability assistance: Wide array of programs need to be examined in light of 21st century challenges*. Washington, DC: United States Government Accountability Office. <http://www.gao.gov/new.items/d05626.pdf>.

Federal Legislative Efforts to Expand Savings Options for Individuals with Disabilities

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People with disabilities face a number of barriers to saving assets for self-sufficiency. Current asset limits tied to eligibility for public support programs restrict individuals' and families' access to the tax-advantaged savings tools available to the general population. Together with income limits, these are a significant disincentive to work. The few savings options designed specifically for people with disabilities have limited functionality, particularly for low- and moderate-income families. Additionally, many of the nonprofits and financial companies providing asset-building products and services to low-income customers have not yet adapted them to the disability market. These factors contribute to a cycle of poverty for many individuals with disabilities that dramatically limits their economic opportunity and their access to self-determination. Despite large public expenditures on disability programs, individuals with disabilities are generally hindered from participating in the economic mainstream. Consider the following:

- According the Bureau of Labor Statistics (BLS), in June 2010, only 21.7 percent of people with disabilities were participating in the work force compared to 70.5 percent of people with no disability. Of the subset of people with disabilities who were participating in the workforce, 14.4 percent were unemployed compared to the national average unemployment rate of 9.4 percent.
- The National Disability Institute reports that only 21 percent of taxpayers with disabilities have incomes over \$40,000.
- Working-age adults with disabilities are three times more likely than their nondisabled peers to live at or below the poverty line.

Progressive, disability-friendly public policy is critical to encouraging people with disabilities to work, save, and participate in the nation's economy. This paper critiques existing policies that deter employment and saving among people with disabilities and reviews the limitations of the currently available savings vehicles. It also describes proposals currently before Congress aimed at tackling policy disincentives and expanding savings options. In the final section, the paper describes the prospects for each legislative proposal.

Asset and Income Limits

Individuals with disabilities often require long-term services and support provided by Medicaid, income assistance from the Supplemental Security Income (SSI) program, as well as other assistance through

federal and state programs. Asset limits greatly restrict individuals' ability to save and improve their well-being. Current Social Security regulations restrict Medicaid support for persons with disabilities who have accumulated more than \$2,000 in countable assets (\$3,000 for a married couple). These limits have not changed since 1989. Persons with disabilities and their family members often face a stark dilemma: Either set aside the total amount of resources necessary to provide care for a person with a disability over their lifetime, or rely exclusively on public assistance. Even those not currently on public support may be concerned with maintaining eligibility for public programs, in the event they would like to use them in the future. Parents of children with disabilities may decide against saving for their child in order to avoid jeopardizing their child's eligibility for Medicaid, SSI, and other means-tested programs.

For people receiving SSI benefits, earnings over the Substantial Gainful Activity (SGA) level can cause a loss of benefits. The SGA level for 2009 was \$1,640 for the Blind and \$980 for people with other disabilities. As such, individuals with disabilities may also face a major conflict around work: Either work significantly more hours, generating income and building assets to become partially self-sufficient; or work significantly fewer hours, if at all, in order to maintain eligibility for public programs. Many individuals and families decide to work just a few hours a week or stay out of the workforce altogether. According to the Social Security Administration, only 5.5 percent of the working-age population (those 18 to 64 years of age) receiving SSI worked in December 2008.

Entitlement programs do not offer realistic, customized strategies that promote optimal self-sufficiency by encouraging work and savings while simultaneously providing needed ongoing support. Individuals who do work, generate income, and save for their future are penalized through the reduction or outright elimination of support. Yet, for many, employment and savings may never provide the income necessary to live independently and plan for the future. Ultimately, asset and income limits deter many from seeking meaningful education or employment opportunities. Thus, a vicious cycle of poverty among individuals living with disabilities continues.

This welfare paradigm is characterized by low expectations and a culture of compliance in which individuals with disabilities are treated primarily as consumers of services and public assistance. From a fiscal perspective, the paradigm may allow public expenditures to be controlled, but it does nothing to help reduce them. This model comes at a cost to individuals with disabilities and to society as a whole. As economist Jonathan Gruber notes, "When individuals reduce their labor supply in order to become poor and qualify for (or in this case maintain) cash welfare, social surpluses fall because fewer goods are produced. A key component of the efficiency-equity trade-off is the social surplus (efficiency) lost due to reduced labor supply by welfare recipients."¹

¹ Gruber, 2007.

Current Savings Tools

Disability advocates have long argued for additional savings tools designed specifically for people with disabilities and their families that would offer the flexibility, portability, and tax advantages available to other Americans. Currently, only a few savings vehicles are available for individuals with disabilities. These products have limited features, and many cannot be used by people on public support because of the income and asset limits associated with these programs. The primary savings options available are special needs trusts, pooled trusts, and individual development accounts (IDAs). Each of the savings tools has its own advantages and limitations.

Special Needs Trusts

Assets deposited into special needs trusts are treated for tax and legal purposes as assets held by the trust rather than the individual, and therefore are not counted for purposes of the asset tests that are associated with determining eligibility for publicly funded cash assistance and entitlement programs. Unlike pooled trusts (discussed below), the assets held in a special needs trust are dedicated solely to the benefit of a single special needs beneficiary and are not held collectively for multiple individuals. These trusts are created and regulated at the state level. They can be expensive to set up and maintain, because the declaration of the trust document must be drafted by an attorney and updated if a family moves to another state. Special needs trusts are taxed at the highest individual tax rate, but they do not have contribution limits, and there are few restrictions on how the assets held in the trust may be spent. If a special needs trust is set up as a third-party trust, then funds remaining upon the death of the beneficiary are not subject to use in any Medicaid reimbursement, also known as a “Medicaid payback.”²

Pooled trusts

Unlike special needs trusts, which are created for the benefit of an individual beneficiary, pooled trusts are established and maintained by nonprofit disability organizations for groups of beneficiaries. Individuals with disabilities deposit assets into an account owned and controlled by the nonprofit organization, and that organization pools the assets of each account for investment and management. Pooled trusts are fully taxable, require set-up and maintenance costs, and are regulated at the state level. Because the assets belong to the nonprofit organization rather than to the individual with a disability, the assets in a pooled trust are not counted for purposes of any asset tests tied to eligibility for publicly funded cash assistance and entitlement programs. Similar to special needs trusts, there are no contribution limits for pooled trusts, and the allowed expenditures of the assets held in the accounts are expansive. The set-up fees can be lower for pooled trusts than for special needs trusts, and the

² A Medicaid payback is a provision in certain types of savings vehicles requiring funds remaining in the accounts at the individual’s death to be returned to the state Medicaid program up to the value of services provided to the individual over his or her lifetime.

organizations that maintain the trusts assist individuals with the maintenance of their accounts. A portion of any funds left in the account after the beneficiary's death remains in the account for the benefit of other participants before a Medicaid payback requirement is applied.

Individual Development Accounts (IDAs)

IDAs are matched savings accounts created to help low-income individuals and families save, build assets, and enter the financial mainstream. A sponsor organization (often a nonprofit) holds the account at a financial institution and “matches” participant contributions (the match is usually one to four times the size of the participant's contribution). The assets held in an IDA are restricted for certain uses, usually the purchase of a first home, paying for post-secondary education, or starting a small business. As such, IDAs reward the monthly savings of working-poor families. IDAs are taxable accounts, although the matching funds may be exempt from federal income taxation as gifts in certain circumstances. Organizations that operate IDA programs often couple the match incentive with financial literacy education, training, and case management. IDAs can be a helpful tool for persons with disabilities, because assets maintained in the account do not count toward asset limits tied to eligibility requirements for federal and state entitlement programs. Only a small number of IDAs are available in each state. Early numbers indicated a small uptake among individuals with disabilities, with fewer than 50 individuals with disabilities opening an IDA by the end of 2009.³

Current Policy Initiatives

Many individuals with disabilities and their families have been searching for ways to save for the unique, ongoing long-term services and support that individuals with disabilities often require without jeopardizing the individual's eligibility for benefits. Several legislative proposals have been introduced in the 111th Congress that would significantly expand the financial savings options of individuals with disabilities. Below we provide a brief overview of these proposals and discuss opportunities to enhance them to ensure the greatest opportunity for savings among individuals with disabilities.

The Achieving a Better Life Experience (ABLE) Act

The Achieving a Better Life Experience (ABLE) Act (H.R. 1205 and S. 493) is the only proposed legislation focused on promoting savings and asset development opportunities specifically for people with disabilities. The ABLE Act would provide individuals and their families control over savings accounts that could accrue assets without jeopardizing their eligibility for Medicaid, SSI, or other public assistance. There are several distinct advantages to these accounts. First, earnings would accrue tax-free. Withdrawals from ABLE accounts would not be taxed as long as they are used to pay for the individual's qualified expenses. Second, ABLE accounts would differ from other savings instruments with tax

³ National Disability Institute, www.ndi-inc.org.

advantages because they would provide substantial flexibility. Any individual with a disability or their parent or guardian could hold and control the account. Third, ABLE accounts are designed to be easy and inexpensive to open, like a basic savings account. Fourth, ABLE accounts would be created and regulated at the federal level, ensuring that they are portable for individuals and families who move across state lines.⁴ Finally, the ABLE Act considers the unique situations of families with children who acquire a disability later in life and allows them to roll-over funds from a traditional college savings account into an ABLE savings account without penalty. Specific details of the proposed ABLE accounts include:

- **Eligible Expenses**—ABLE accounts are designed to allow the assets held in the account to be used for a broad range of expenses. Funds are not limited to use in adulthood or retirement but can be used for many expenditures whenever they are needed. This flexibility is necessary for planning ahead when families are not yet sure how independent their child will become. Although the list of eligible expenses is not as expansive as that for special needs trusts or pooled trusts, the ABLE account can fund a variety of essential expenses, including educational expenses; medical and dental care; health, prevention, and wellness expenditures; employment training and support; assistive technology; personal supports services; transportation; housing; and other expenses for life necessities.
- **Flexibility and Portability**—Individuals and families with ABLE accounts can roll-over these funds into an individual trust or pooled trust if these trusts would better meet their needs. ABLE accounts can be managed by pooled trusts if the individual or family so chooses. Similar to Medicaid trusts, funds remaining in the accounts at the individual's death would be applied toward Medicaid paybacks.

There are possibilities for strengthening the tax incentives provided in the ABLE Act. Under the current versions of the bill, an individual with a disability who is the beneficiary of an ABLE account is entitled to a tax deduction for the amount he or she contributes to the ABLE account, up to a maximum of \$2,000 per year. The deduction phases out as income increases until it reaches zero for individuals with income exceeding \$35,000, heads of household with income exceeding \$52,500, and joint filers with income exceeding \$70,000.

Taxpayers who do not itemize their deductions (the vast majority of lower- and middle-income taxpayers) cannot make use of the proposed tax deduction. Those receiving Medicaid and SSI do not ordinarily have significant taxable income, and therefore cannot make use of the proposed deduction. For these reasons, we recommend that the proposed tax deduction be eliminated or replaced with a

⁴ ABLE Accounts may be established either as trusts or as custodial accounts. Like other tax-advantaged savings vehicles (e.g., Coverdell Education Savings Accounts), the governing instrument establishing the account would be an Internal Revenue Service form created specifically for ABLE Accounts to comply with federal law (see, e.g., IRS Form 5305-E and 5305-EA).

refundable tax credit, which reduces the amount of tax owed on a dollar-for-dollar basis. If the resulting amount of tax owed is negative, a taxpayer may apply for a refund.

Additionally, language should be added to any tax credit provision requiring that refunds made to individuals as a result of the new tax credit be deposited directly into the ABLE account rather than paid to the individual. This would help ensure that the refund does not affect the individual's ability to qualify for Medicaid or SSI. The tax credit should also have income phase-outs and a cap.

The Savings for Working Families Act

The government established the first IDA program under the Assets for Independence Act of 1998. Most states include IDAs in their Temporary Assistance for Needy Families (TANF) Statute. One benefit of opening an IDA is that savings in the account do not count as assets for the purpose of qualifying for state or federal benefits.

Today many IDA advocates across the country are working to advance state policies and expand funding for IDAs so that even more Americans will be able to benefit from this program. The Savings for Working Families Act of 2009 (SWFA) (H.R. 2277 and S.985) would authorize the creation of an additional 2.7 million in IDAs and provide \$120 million over a 10-year period to nonprofit organizations providing financial education to low-income individuals. Passage of this important legislation would result in a three-fold increase in the number of available IDAs and a six-fold increase in the resources for financial education compared with the previous legislation.

Since the first federally funded IDA program began 10 years ago, the IDA field has grown dramatically, and today more than 1,100 sites provide IDAs to more 83,000 savers. More than 35,000 people have graduated from the program, having purchased a major asset and completed courses in financial education. The SWFA would expand IDAs by providing a tax credit to financial institutions that match the savings of low-income families on a dollar-for-dollar basis. Despite the growth of IDAs, to date these programs have served only a small proportion of lower-income individuals and families. If the SWFA is enacted, the additional resources would fund at least 6,000 new accounts per state, and eligible donor organizations could apply for additional accounts. Expansion of IDAs would increase the opportunities of individuals with disabilities to build savings and achieve financial security and independence.

Revisiting Asset Limits

This year, Representative Niki Tsongas (D-MA) introduced the SSI Savers Act of 2010 (H.R. 4937), legislation that would address concerns around the extremely low asset limits of the federal disability programs. H.R. 4937 would make the following modifications to the SSI program:

- Increase limits on countable resources to \$5,000 for individuals and \$7,500 for couples and index these limits to inflation.
- Exclude any assets (up to \$10,000 for individuals and \$15,000 for couples) included in a

qualified retirement plan, trust, education savings account, savings bond, or individual development account.

- Eliminate the requirements that SSI recipients apply for periodic payments from deferred compensation arrangements.
- Exclude from income one-third of distributions from deferred compensation arrangements.

Representative Tsongas worked closely with the Corporation for Enterprise Development (CFED) and other national asset development organizations in the drafting of H.R. 4937. Disability advocates have provided the following five recommendations for improving and clarifying the intent of the legislation:

1. Increase asset limits five-fold, to \$10,000.
2. Ensure that asset and income limitations outlined in the legislation for Social Security programs are applied comprehensively to financial eligibility tests under all federally supported programs, including Medicaid.
3. Strengthen language of the current bill to ensure that it will cover alternative financial savings tools and new types of accounts yet to be created.
4. Reference the inclusion of IDAs operating under the auspices of the Personal Responsibility Act to ensure that the legislation covers all TANF IDA accounts.
5. Clarify that anything that is excluded as an asset under the legislation will also be excluded when converted to income. This would ensure that any withdrawn funds be income-exempt up to the level that they were resource-exempt prior to their withdrawal.

Legislative Outlook

These three legislative proposals are representative of a new era in federal legislative initiatives aimed at improving the economic self-sufficiency and long-term financial security of individuals with disabilities and their families. As Congress heads into the election cycle, disability advocacy organizations see a significant opportunity to increase momentum surrounding these legislative proposals.

The ABLE Act was introduced in the U.S. House of Representatives and Senate in February 2009.⁵ The legislation currently enjoys tremendous bipartisan support, with over 195 cosponsors in the House and 25 cosponsors in the Senate. The Joint Committee on Taxation scored the ABLE Act as costing \$1.6 billion over ten years. This cost presents a gradual increase each year as people learn about the accounts and start to establish them for personal use until the annual costs reach an estimated \$316 million.

⁵ H.R. 1205 was introduced by Representatives Ander Crenshaw (R-FL), Kendrick Meek (D-FL), Phil Hare (D-IL), Patrick Kennedy (D-RI), Gregg Harper (R-MS), and Cathy McMorris Rogers (R-WA). S.493 was introduced by Senators Robert Casey (D-PA), Chris Dodd (D-CT), and Orrin Hatch (R-UT).

The Savings for Working Families Act was reintroduced in the U.S. House of Representatives and Senate in May 2009.⁶ The legislation currently has 10 cosponsors in the Senate and 18 cosponsors in the House. In the 110th Congress, the SWFA (then S.871/H.R. 1514) possessed widespread bipartisan support, with a record level of 127 cosponsors (including 27 Senators and 100 House Representatives). At that time, the Congressional Budget Office scored the legislation as costing \$1.35 billion over a 10-year period. The Obama Administration included passage of SWFA in the President's 2009 proposed budget, but there has yet to be any movement on the legislation in the Congress.

Representative Tsongas introduced the SSI Savers Act (H.R. 4937) on March 24, 2010. The legislation was referred to the House Ways & Means Committee and currently has five cosponsors. There have been no announcements of plans to introduce a companion bill in the Senate.

If passed, these legislative proposals would create a significant opportunity for financial services companies and asset development organizations to engage in the goal of helping individuals with disabilities participate actively in the U.S. economy through working, earning, and saving. These proposals provide a pathway for empowering individuals with disabilities to attain greater economic self-sufficiency.

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References

U.S. Department of Labor, Bureau of Labor Statistics, *Labor force statistics from the Current Population Survey*, <http://www.bls.gov/cps/cpsdisability.htm>.

Gruber, Jonathan. 2007. *Public finance and public policy* (Second Edition). New York, NY: Worth Publishers.

National Disability Institute. Real Economic Impact Tour. <http://www.realeconomicimpact.org/REI-Tour.aspx>.

Social Security Administration. *SSI annual statistical report, 2008*. Baltimore: Office of Research, Evaluation, and Statistics. http://www.ssa.gov/policy/docs/statcomps/ssi_asr/2008/ssi_asr08.pdf.

⁶ H.R. 2277 was introduced by Representatives Earl Pomeroy (D-ND), Allyson Schwartz (D-PA), Joseph Pitts (R-PA), and Kevin Brady (R-TX). S.985 was introduced by Senators Blanche Lincoln (D-AR), Joe Lieberman (D-CT), John Kerry (D-MA), Jim Bunning (R-KY), Olympia Snowe (R-ME), and Susan Collins (R-ME).

Increasing the Employment Rate of People with Disabilities

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Twenty years after the passage of the Americans with Disabilities Act (ADA), the more than 50 million people with disabilities in the United States continue to face pervasive unemployment and underemployment, and a disproportionate number live in poverty. This paper examines topics related to the employment of people with disabilities, including legal protections against discrimination in employment, recent employment statistics, and current efforts to improve employment outcomes. It also explores how increasing the employment of people with disabilities would increase the disability market and strengthen the purchasing power of this group and the economy overall.

The Americans with Disabilities Act and Employment

The ADA was signed into law on July 26, 1990, and was intended to provide a “clear and comprehensive national mandate for the elimination of discrimination” against people with disabilities.¹ The ADA’s employment provisions were modeled on provisions barring discrimination in federal employment contained in the Rehabilitation Act of 1973, as amended. The Rehabilitation Act also provides for affirmative action in the hiring of people with disabilities by federal agencies and federal contractors.

As originally adopted, the ADA included a clear declaration that employers shall not “discriminate against a qualified individual with a disability because of the disability of such individual in regard to job application procedures, the hiring, advancement, or discharge of employees, employee compensation, job training, and other terms, conditions, and privileges of employment.” A disability was defined as an impairment that substantially limits a “major life activity.” A qualified individual with a disability was further defined as one who “with or without reasonable accommodation, can perform the essential functions of the employment position that such individual holds or desires.” The ADA required employers to provide a reasonable accommodation, if such accommodation was necessary to allow an employee to perform the essential functions of the job, unless it caused undue hardship to the employer. A few examples of the types of reasonable accommodations an employer may undertake include making existing facilities readily accessible to and usable by individuals with disabilities, modifying work schedules, and providing qualified readers or interpreters.

Congress’s intent in passing the ADA was subsequently stymied by a series of restrictive court decisions that narrowed the scope of who qualified for protections under the ADA. In *Sutton v. United*

¹ In addition to prohibiting discrimination in employment, the ADA prohibits discrimination in the provision of state and local government services, including public transportation and public accommodations. The ADA also provides for access to telecommunications services by requiring the establishment of telecommunications relay services and closed captioning of public service announcements.

Airlines and two related decisions in 1999, the Supreme Court ruled that people who are able to function well with the help of “mitigating measures” such as eyeglasses or medication should not be considered substantially limited, even if they are substantially limited in their natural or unmitigated state.² In practical terms, this meant that people with a host of disabilities and chronic illnesses were no longer covered by the Act. As such, they were no longer entitled to receive the accommodations that might be necessary for them to control and treat their conditions. For example, a diabetic who needed periodic breaks to eat and take medication might no longer be entitled to a scheduling modification as a reasonable accommodation.

The effects of the court decisions were magnified by other rulings, notably the 2002 Supreme Court decision in *Toyota v. Williams*, in which the courts narrowed the scope of what constitutes a major life activity. The plaintiff in *Williams* was an assembly line worker in a car manufacturing plant who, as a result of carpal tunnel syndrome and tendonitis, could no longer perform certain functions of her job. The Supreme Court held that in determining whether an individual is “substantially impaired” and therefore covered by the ADA, the proper test is whether the individual has an impairment that prevents or restricts the individual from doing activities that are “of central importance to most people’s daily lives,” such as performing household chores, bathing, brushing one’s teeth, and dressing. The Supreme Court expressed doubt that work constituted a major life activity under the ADA.

In 2008, advocates for people with disabilities were successful in getting the ADA Amendments Act passed and signed into law. The ADA Amendments Act rejects the findings of the Supreme Court holdings in *Sutton* and *Williams* by defining major life activities to be “construed in favor of broad coverage of individuals” and stating that mitigating measures (other than ordinary eyeglasses or contact lenses) are not to be considered in determining whether an impairment substantially limits a major life activity. The ADA Amendments Act recreates a solid foundation on which to build policies and programs focused on bringing more people with disabilities into the economic mainstream.³ Such initiatives are critical to increasing labor force participation and employment among people with disabilities, and ultimately to strengthening their economic well-being.

Employment Statistics

Too few people with disabilities are employed. In 2008, the Current Population Survey (CPS) began including questions aimed at identifying the population with disabilities. The CPS is a monthly survey of households conducted by the U.S. Census Bureau for the Bureau of Labor Statistics (BLS). It provides a comprehensive body of data on the labor force, employment, unemployment, and persons not in the labor force. The data reported below are for the civilian, non-institutional working-age population (between 16 and 64 years of age). These data are not yet seasonally adjusted, as there are not sufficient years of data to make such adjustments.

² The two companion cases were *Murphy v. United Parcel Service* and *Albertson’s Inc. v. Kirkinburg*.

³ The Equal Employment Opportunity Commission is in the process of issuing new regulations to reflect the changes in the Act.

Labor Force Participation Rate

In June 2010, 7.4 percent (or 14,636,000 individuals) reported a disability. Of these, 33.7 percent participated in the labor force (i.e., were either working or actively looking for work). By comparison, among the 184,387,000 individuals with no disability, 77.7 percent participated in the labor force. While the labor force participation rate is helpful for identifying what percentage of the population is engaged in work or looking for work, it does not tell us what part of a population is employed, as explained below.

Unemployment

The unemployment rate gauges the tightness of the labor market, or how hard it is to get a job. In June 2010, the unemployment rate among people with disabilities was 15.6 percent. This is compared to an unemployment rate of 9.6 percent for people with no disability. One limitation of the unemployment rate measure is that it considers only people who are participating in the labor force and does not tell us anything about the number of people who may have become discouraged and have given up looking for work.

Employment-to-Population Ratio

Another way to measure employment status is to look at the percentage of working-age people who are actually working. In June 2010, this ratio was 28.5 percent for people with disabilities and 70.3 percent for people with no disability.

Taken together, the employment-to-population ratio, labor force participation rate, and unemployment rate provide a more complete picture of a population's employment situation than any one measure on its own. All three measures show a significant gap between the employment situation of people with disabilities and the employment situation of people with no disability.

Employment statistics can be used to support the development and monitoring of policy goals. Suppose our initial goal is to increase the employment-to-population ratio of people with disabilities by five percent, from 28.5 percent to 33.5 percent. Holding the number of working-age people with disabilities constant, this goal would entail increasing the number of employed working-age people with disabilities from 4,169,000 to 4,903,000—an increase of 734,000 individuals. Over a ten-year period, this would involve employers hiring and retaining an additional 73,400 individuals a year.

Purchasing Power

We know that increasing employment can raise individual and household incomes and thus the purchasing power of a population. To understand how increasing the employment-to-population ratio by five percent can increase the size of the disability market, we look at U.S. Census Bureau data from

the American Community Survey (ACS), which includes measures of population size and incomes for people with disabilities.

According to the 2008 ACS, 12.7 percent of the U.S. population reported a disability. Of these, 91.4 percent lived in households, while 8.6 percent lived in group quarters. Using households rather than individuals as the unit of analysis, there were 113,101,000 total households (including those living in group quarters) in the United States, of which 24.4 percent contained at least one person with a disability.

The ACS asks about household and individual pre-tax income from various sources.⁴ Summing income across households, total U.S. households had pre-tax income of \$8.1 trillion, of which \$1.4 trillion was held by households with at least one person with a disability. If we assume that the relationship between income and spending is the same for households with disabilities as households without disabilities, this suggests that the latter control almost 18 percent of spending in the United States. The pre-tax income of employed people with disabilities was \$274.2 billion compared to \$133.7 billion for people with disabilities who were not employed. This means that the average employed person with a disability had \$37,000 in pre-tax income, while the average non-employed person with a disability had \$12,000 in pre-tax income—a difference of \$25,000.

Before we can complete our calculations of the effect of increasing the employment-to-population ratio on purchasing power, we need to recalculate how many additional people would need to be employed using ACS data. The ACS indicates an employment-to-population ratio of 39 percent (7,362,000 employed individuals). A five percentage point increase in the ACS-based employment-to-population ratio to 44 percent (holding constant the number of working-age people with disabilities) would require hiring an additional 943,000 people.

If we assume that the 943,000 individuals who get jobs increase their pre-tax income by \$25,000, then the five-percent rise in employment for people with disabilities would result in a \$23.5 billion rise in the aggregate pre-tax income of working-age people with disabilities—substantially increasing the purchasing power of people with disabilities and their households. Advocates have long felt that the disability community does not receive as much attention from businesses as it should given its size. Increasing the purchasing power of this group could persuade more businesses to focus on this market, leading to improvements in accessibility, better customer service, and an increase in the use of universal design principles.

⁴ Income sources in the ACS include wages, salary, commissions, bonuses, or tips from all jobs; self-employment income (net income after business expenses) from one's own non-farm or farm businesses, including proprietorships and partnerships; interest, dividends, net rental income, royalty income, or income from real estates and trusts; Social Security Income or Railroad Retirement Benefits; Supplemental Security Income; any public assistance or welfare payments from the state or local welfare office; retirement, survivor or disability pensions; and any other regularly received income (e.g., Veterans' payments, unemployment compensation, child support, or alimony).

Federal and Private Initiatives

The programs and policies of the public sector, nonprofit organizations, and private companies in recent years have yielded compelling individual success stories, yet the employment rate of people with disabilities has not improved since the passage of the ADA. It is time for more comprehensive measures to be instituted. In this difficult economy, people with disabilities are faced with bleak prospects for employment, but there are promising signs.

During its first year and a half, the Obama Administration has taken positive steps towards realizing the federal government's long-standing commitment to providing equal employment opportunity for people with disabilities. On July 26, 2010, the 20th anniversary of the signing of the ADA, President Obama issued an Executive Order on Increasing Federal Employment of Individuals with Disabilities. The order called for the federal government to employ an additional 100,000 people with disabilities over five years. This goal was first announced in Executive Order 13163 signed by President Clinton on July 26, 2000, the tenth anniversary of the signing of the ADA.

The new Executive Order includes specific requirements designed to establish the federal government as a model employer of individuals with disabilities. It requires the Director of the Office of Personnel Management (OPM) to design model recruitment and hiring strategies for agencies to increase employment of people with disabilities. It calls for mandatory training programs for human resources personnel and hiring managers. Further, the order requires every department and agency to develop its own plan for promoting employment opportunities for people with disabilities and to name a senior-level agency official who will be accountable for these plans. The Director of the OPM is required to create a system for regular reporting to the President, the heads of agencies, and the public on agencies' progress in implementing their plans. President Obama also underscored his personal commitment to disability equality by appearing in a public service announcement.

The federal government has also taken positive steps to strengthen the requirements of Section 503 of the Rehabilitation Act. Section 503 requires federal contractors to take affirmative action to employ and advance qualified individuals with disabilities. To date, the government has not enforced the affirmative action requirements for people with disabilities with goals and timetables like those used to enforce the affirmative action requirements for minorities and women. On July 23, 2010, the Office of Federal Contracts Compliance Program (OFCC) issued an Advance Notice of Proposed Rulemaking seeking comments on how it should revise the regulations under Section 503. Almost one-fourth of the civilian jobs in the United States are with companies that are subject to federal affirmative action requirements. Concentrated attention on hiring and advancing people with disabilities in this broad range of jobs could make a significant difference in their employment rate.

The Department of Labor's Office of Disability Employment Policy (ODEP) also provides a number of important services to support the employment of people with disabilities: the Job Accommodation Network, which assists employers in identifying and providing reasonable accommodations to people with disabilities; EARNWORKS, a consulting service that assists employers in recruiting and hiring people with disabilities; and the Campaign for Disability Employment, a collaborative effort to promote positive

employment outcomes by encouraging employers and others to recognize the value and talent people with disabilities bring to the workplace.⁵

Many private-sector companies have committed to voluntary efforts to improve employment outcomes for people with disabilities as part of their diversity and corporate responsibility efforts. Leaders of these companies are deeply committed to being employers of choice, and they are devoting resources to creating inclusive workplace policies and practices. Many companies share their successes and work to develop best practices through national, state, and local business leadership networks. With an enhanced focus by committed leaders and support from the government and nonprofit sector, perhaps we will finally begin to see an increase in the employment of people with disabilities.

In September 2010, Senator Tom Harkin, the Chair of the U.S. Senate Committee on Health, Education, Labor and Pensions, will host a summit in Washington, D.C. with the goal of developing a legislative agenda that can complement some of the efforts underway in the Obama Administration at the State level and in the private sector.

More Can Be Done

When President George H.W. Bush signed the Americans with Disabilities Act into law, he recognized that the ADA “promises to open up all aspects of American life to individuals with disabilities—employment opportunities, government services, public accommodations, transportation, and telecommunications.” While our society has become far more accessible to people with disabilities over the last 20 years, the promise of equal employment opportunity for people with disabilities remains largely unfulfilled. To strengthen the path toward equality and full access for people with disabilities, the public and private sectors will need to work together to increase employment opportunities and to address structural disincentives to employment. People with disabilities should not have to fear losing their health care and other public benefits if they pursue employment. Access to transportation, personal care assistance, education, and training must be improved for people with disabilities to participate fully in the 21st-century workforce. If concerted efforts by the public and private sectors result in a five percent increase in employment for people with disabilities, this will significantly expand the size and purchasing power of the disability market.

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⁵ The American Association of People with Disabilities is a member organization of the Campaign for Disability Employment.

References

Albertson's Inc. v. Kirkinburg, 527 U.S. 555 (1999).

Americans with Disabilities Act of 1990, 42 U.S.C. §§ 12101-12213.

Americans with Disabilities Amendments Act of 2008, P.L. 110-325.

Murphy v. United Parcel Service, 527 U.S. 516 (1999).

Office of Federal Contracts Compliance Programs, *Facts on Executive Order 11246 – Affirmative Action*, <http://www.dol.gov/ofccp/regs/compliance/aa.htm>.

Rehabilitation Act of 1973, 29 U.S.C. §§ 701-794a.

Sutton v. United Air Lines, Inc., 527 U.S. 471 (1999).

Toyota Motor Mfg. v. Williams, 534 U.S. 184 (2002).

U.S. Department of Labor, Bureau of Labor Statistics, *Labor force statistics from the Current Population Survey*, <http://www.bls.gov/cps/cpsdisability.htm>.

U.S. Office of Personal Management. *Federal employment of people with disabilities*. 5 C.F.R. 213.3102(u). http://www.opm.gov/disability/appointment_disabilities.asp.

Handshakes, Not Handouts: Building the Business Case for Inclusion

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The need to increase employment among people with disabilities is more critical than ever. Cornell University reports that the employment rate for people with disabilities is 36.9 percent compared to 79.7 percent for those with no disability (Bjelland, Erickson, and Lee, 2008). Government programs have done little to increase employment for people with disabilities, and certain policies, including asset limits on public programs that strip employees of their benefits when they reach a certain income level, are proven disincentives to work. Legislation has recently been introduced to raise these asset limits, but it is too early to tell whether the bill will have enough support.

Major companies that otherwise promote diversity in their hiring strategies have, for the most part, long neglected this sector. Decades ago, legal and political activism broke down many of the barriers hampering the advancement of women and racial minorities in the workplace. Fearing lawsuits, fines, and boycotts, corporations complied with new Civil Rights laws. Few corporations are as worried about activism or legal reprisals from the fragmented community of people with disabilities, in part because there is so little "bite" in the Americans with Disabilities Act (ADA)—only 10 percent of complaints have been successful, and settlements have been small. The ADA Amendment Act of 2008 is likely to foster additional employment for people with disabilities, but it is too early to assess the scale of its effects. In addition, the fragmentation of the "disability community" has all but ruled out the potential for boycotts or other consumer-based measures that other minorities can wield as a stick to threaten corporations.

Existing and new public policy, public programs, and philanthropic programs will not be enough to bring people with disabilities into the economic mainstream. Businesses choosing to employ more people with disabilities will play a crucial role. But private companies should not do this simply because it is "the right thing to do." Businesses can consider strategies to hire and integrate employees with disabilities successfully into the company as a means to reach the large, largely untapped disability market. This is a strategy aimed at increasing revenues and keeping an organization on the cutting edge of innovation. Below I describe the size of the disability market and make suggestions for developing a disability-inclusive strategy that informs hiring practices, product design and marketing, public relations, and, ultimately, corporate culture. These suggestions can help businesses as well as the community-based organizations supporting companies' efforts to employ people with disabilities.

The Business Case for Targeting the Disability Market

The carrot of sales, more than the sticks of regulation and reprisal, makes a compelling case for a commitment to diversity. Businesses have long understood the value of tapping new minority markets to expand revenues. Based on the demographics of the disability population, there is reason to believe there are large untapped revenues here as well. According to the U.S. Census Bureau, the 54 million people with disabilities represent approximately \$1 trillion dollars in aggregate income and \$220 billion

in discretionary spending power. To put the numbers into perspective, they add up to more than the African-American, Latino, and gay markets combined. The disability market offers double the fabled spending power of teens and more than 17 times the spending power of tweens (8- to 12-year-olds), two of the most avidly pursued demographic groups. The American Association of People with Disabilities and Public Opinion Research Inc. report that more than 70 percent of members choose to buy from retailers that support people with disabilities, while a similar survey from the Center for Social Development and Education at the University of Massachusetts at Boston noted that 92 percent of participants with disabilities felt more favorable toward companies that hire individuals with disabilities, and 87 percent would give their business to those companies (Siperstein et al. 2006).

This is too big a phenomenon to be styled a "niche." In addition, customers and applicants with disabilities participate in three major consumer movements: the rise of the knowledge worker as predicted by Peter Drucker, the demand-driven consumer rights revolution, and the Baby Boomer generation with its large economic clout. In terms of size, disability is the largest minority market. In terms of growth, between 1990 and 2000 this group increased 25 percent, faster than any other minority group, including the rapidly growing Latino demographic.¹ Companies are beginning to notice and line up for their part of the pie. Here is the pitch as Karen Quamenn of Medtronic and the Business Advisory Committee to the National Spinal Cord Injury Association delivers it: "If I held up five \$20 bills and said this one is from the black community, this from Latino, this from gay and lesbian, this from women, and this from people with disabilities, which of these is any less valuable than the other?"²

There is also potential payoff to being the first to tap a massive market in terms of customer loyalty and profits. IBM continues to score high on disability consumer trend reports, because they were among the first to establish a comprehensive strategy to hire people with disabilities. They discovered that moving into the vanguard on the employment front brings a powerful group of dedicated customers and workers. "Doing the right thing" in terms of meeting the need of customers with disabilities can have real payoff in other ways. Consider AT&T, which, according to insiders, was successful in securing regulatory approval for a multi-billion dollar merger in 2005 partly by demonstrating it was way out in front of its target company, BellSouth, when it came to serving deaf cellular users. This case is emblematic of the high-stakes outcomes that investors and directors cannot afford to ignore. A stronger corporate image is also a part of the opportunity package, and an increasingly important consideration in light of activist consumers and investors.

Strategy

How does a business tap this market? One way is to develop a comprehensive diversity strategy that affects all aspects of a company's activities, from hiring to product design and marketing. The comprehensive nature of the strategy promotes success in hiring and integrating people with disabilities into a company, as well as helping the company develop products that successfully meet the needs and

¹ Author's interview with Tari Susan Hartman-Squire, June 2004.

² Personal interview with the author, October 2005.

preference of the disability market. Such a strategy includes a public relations effort to get the word out about the company's commitment to diversity.

Hiring

The names of companies with disability-forward hiring strategies are well-known, especially to the disability community: IBM and Microsoft have matched product launches to job programs; Merrill Lynch, Bank of America, and SunTrust sign up new clients from the same communities where they hire. These positive reputations were not gained by accident. They involved the step-by-step development of a diversity strategy that starts with hiring and goes beyond.

Where do you start? The most successful corporations go to the sources. They find candidates at employment fairs for applicants with disabilities. The best-attended of these are sponsored annually by Gallaudet University, the National Technical Institute for the Deaf, Career Opportunities for Students with Disabilities (COSD) based at the University of Tennessee, the Job Accommodation Network, the Office of Disability Employment Policy (ODEP) of the Labor Department, and the career services offices of universities with a strength in the disability area, such as the University of Minnesota and University of California system. Resumes received through these sources can legally be coded by a recruiter for diversity based on the intermediate source.

Some company names pop up again and again in conversations on disability and employment. Among the strongest are those in the tech, telecommunications, and banking sectors—partly because they have the tools to make knowledge-focused jobs accessible and partly because they discovered long ago the profits that accrue from recognition within the disability community. According to company annals, IBM hired its first employee with a disability in 1914. Four decades later the company invented remote-controlled keyboards and voice-activation tools, and has been churning out assistive technology products ever since. Today it is considered one of the most aggressive recruiters in the disability community. Right alongside IBM is Microsoft, which has a massive cultural commitment to disability and has posted strong numbers in terms of hiring.

The basic literature on hiring people with disabilities is straightforward and little changed since the passage of the ADA in 1990. The caveats have been in place for nearly two decades, so HR interviewers are by now familiar with the constraints that the ADA stipulates, particularly the proscription against asking directly about a disability or medical condition. Companies that have moved to more advanced thinking on disability address the mindset of the interviewer. Interviewers may incorrectly assume that people with disabilities are incapable of handling certain jobs, and there is a tendency among many who have little experience in this area to assume that the company might not have any jobs that would be right for a person with a disability. The trouble with this prejudice is that it ignores the fact that a job is a job, and then it categorizes the interviewee as someone who needs to be put into a “special” spot.

It would be pointless to instruct interviewers not to be judgmental—their job is in part a moment-by-moment string of judgments that must be made quickly, but these should not be *medical* judgments, for which most recruiters are unqualified. Along these lines, the Department of Justice's Office of

Disability Employment Programs recommends that non-disabled interviewers keep a lid on their imaginations and emotions, including the tendency to indulge in amateur medical diagnoses or psychotherapy when meeting a person with an unknown but apparent disability. As compassionate as these suppositions might seem, they pull the focus away from the skills and capabilities of the interviewee and focus on the medical condition. The ODEP checklist also warns: “Don’t speculate or try to imagine how you would perform a specific job if you had the applicant’s disability.”

Recruiting begins even before a position opens. Web sites and printed materials that offer job postings should be in alternative formats that are accessible, and efforts should be made to link or forward postings to service sites with disability constituencies. Employers big and small ought to develop a rapport with the local disability organizations, training programs, and government offices where employment counseling is offered. Most universities now have a well-staffed office of disability services, dedicated in part to adjudicating requests for note-takers or extra time on exams. These would be perfect liaisons for corporate recruiters, who could rely on the campus connection to identify interviewees. Internships and other on-campus recruiting efforts can help create a pipeline of employment candidates. Along these lines, major corporations can become familiar with the colleges that attract strong students with disabilities because of their particular academic programs or services for such students.

Other strategies companies can take include directing executive search firms to go through the employment nonprofits mentioned above or use subcontractors that employ people with disabilities—many large corporations set the standards for their subcontractors when it comes to whom they hire, how much they pay, and the conditions under which the work is to be done.

Product Design and Marketing

Companies looking to develop products that appeal to customers with disabilities start by assembling demographics to understand what market segment (the specific disability, customer age, income level, etc.) offers the highest potential consumer demand or otherwise makes the most sense for the company to appeal to. The company can partner with a disability service organization that provides coaching on the customer base and relationships to its membership. Disability-specific focus groups and market research can inform preferences around products as varied as cell phones, cars, and soap. Internal design and marketing teams get up to speed on disability codes, including linguistic etiquette. The special characteristics of the product are trumpeted to the disability community and other sympathetic consumers. Crossover possibilities for multiple uses of the technology or other special characteristics of the product can be explored. A marketing campaign is launched. The press is alerted and retail outlets are encouraged to get on the bandwagon with their own image-boosting, disability-friendly efforts. Advertising and promotion crafts a message that will attract the community’s approval. The company’s commitment to customers and employees with disabilities itself becomes part of the message.

Public Relations

The public relations strategy is part of building a disability presence, candidly affirming the ends-driven motivation behind accommodating both employees and customers. It complements the marketing initiative in cost-effective ways that managers instantly recognize. It offers a way to complete publically the internal project of articulating the company's disability agenda. Word-of-mouth conveyed via social networks, blogs, list-serves, and specialty press are key to disability marketing. In 1998, Mattel scored with Share-a-Smile Becky (Barbie's companion in a wheelchair). Just a few weeks after CNN had aired its unusually lengthy two-minute piece about the product launch, the doll was sold out. Now good news is spread through social media (e.g. Facebook) and should include information about accessibility and disability-forward hiring as a way to build loyalty and interest in the community.

Conclusion

A comprehensive diversity strategy ultimately contributes to the strength and affects the very culture of a company. In finding ways to effectively integrate employees with disabilities into the company and promote their success, the business must refine its focus to draw on the expertise and experience of the new employees. Two concepts are particularly useful for helping change a company's culture around diversity and inclusiveness of employees with disabilities: the architectural term "wayfinding" and the anthropological and economic paradigm of a "trading zone."

An important aspect of integrating employees with disabilities into the company involves building an accessible workplace. The older version of accessibility involved meeting ADA-directed guidelines for entrances, bathrooms, and fire exits. A more useful approach is to elicit the input of "user-experts," people with disabilities who participate in the design process, to create workspaces that provide employees with disabilities the same types of access and space available to other employees.³ Businesses can also adopt a principle known as "wayfinding." The term was introduced by architect Kevin Lynch in his 1960 book *The Image of the City*, and rapidly gained popularity in the Universal Design movement because of what it offered to architects designing spaces for blind users. It emphasizes legibility and ease of movement through space. In the built environment this involves the comprehensive deployment of materials, technology, light, sound, form, and texture to guide, for example, a blind colleague along the corridors and offices of the building. While there are options like infra-red-based systems delivering aural directions to headphones (similar to a museum Acoustiguide), some options are cleverly low-tech as well. It is not simply a matter of getting someone through the front door. Once inside, it is important that a person with a disability is offered choices and guidance along the same number of routes any other colleague might pursue.

³ One of the most successful ideas used at organizations like Microsoft, Bank of America, and Northwestern University is the cultural-affinity group. These groups depend on self-identification and meet regularly to discuss complaints as well as other issues. Microsoft has three such affinity groups for people with disabilities (blind, deaf, and ADD/ADHD, the largest). The hope is that the on-campus presence of these groups makes workers feel more confident about gathering and discuss concerns and opportunities.

A focus on wayfinding goes beyond design of the physical space. It is an integrated, multi-pronged organizational approach, calling on human resources, management, marketing, finance, and information technology (the interface between virtual and real design for many workers with disabilities, at least half of whom rely heavily upon computers). Good wayfinding literally and figuratively invites employees into the heart of the company. A route must accommodate the disability, but it should not be marked at each turn as specific to the disability, like the designated wheelchair seat on the bus. Nothing is more damaging than the assumption that people with disabilities must be relegated to a desk job, out of sight.

A second key concept is that of a “trading zone,” where people from different disciplines within a company meet to exchange information about strategies to hire, retain, and promote people with disabilities. The equation depends upon the perception of disability as a culture that can be pursued as a market and talent pool. The trading zone, as in the anthropological and economic examples, is a focus of translation and exchange for symbiotic relationships. As groups begin to trade, the more frequently they interact, the more freely they communicate. Over time, contact yields understanding, leading to fluency in the lingua franca and the trust essential to successful business.

Trading zones do not in and of themselves solve the equality problem, but they embody an implicit faith in the value of trading information, and the process of trade brings the partners closer together. Corporations are redefining their identities in terms of maximizing the meaning of what they do and enhancing their reputations in terms of accountability. Where is the trading zone? It must be in both the workplace and the marketplace. Who is in on it? Both the entry-level job seeker and the chief executive officer must be involved. All the different departments of the corporation, from human resources to marketing to public relations to legal have to be there, as well as managers and supervisors. So should the nonprofit service providers, the government policymakers, and teachers who prepare the workers of the future. The ideal trading zone is an accessible place of visibility for both people with disabilities and their non-disabled business partners. It is a place for handshakes, not handouts.

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Agenda

Sell to the community from which you **hire**
Communicate your commitment in labels, advertising, packaging, press campaigns
Know the customer's needs and comfort level
Pitch the people or products, not the disability
Enlist the expertise of the nonprofits and the support of top brass
Avoid patronizing or insulting language and images
Make your Web site accessible and ensure alternative formats for promotional materials
Edit your copy for Web sites, sales materials, media kits, and presentations to ensure people-first language
Have a lineup ready of trusted in-house sources with disabilities who can represent the company
Avoid using philanthropy to deflect discrimination accusations from the press and advocates
Audit the workplace for design shortcomings based on a range of disabilities

References

Berkowitz, E. 1987. *Disabled policy: America's programs for the handicapped*. New York: Cambridge University Press.

Berkowitz, M. and M. Hill, eds. 1986. *Disability and the labor market*. Ithaca, New York: ILR Press.

Bjelland, M.J., W.A. Erickson, and C.G. Lee. November 8, 2008. *Disability statistics from the American Community Survey (ACS)*. Ithaca, NY: Cornell University Rehabilitation Research and Training Center on Disability Demographics and Statistics (StatsRRTC).

U.S. Department of Labor, Bureau of Labor Statistics, *Labor force statistics from the Current Population Survey*, <http://www.bls.gov/cps/cpsdisability.htm>.

Burkhauser, Richard V. and Robert H. Haveman. 1982. *Disability and work: The economics of American policy*. Baltimore: Johns Hopkins University Press.

Burkhauser, R. V., M.C. Daly, A.J. Houtenville, and N. Nargis. 2002. Self-reported work limitation data: What they can and cannot tell us. *Demography*, 39(3).

Fine, Michelle and Adrienne Asch, eds. 1988. *Women with disabilities: Essays in psychology, culture and politics*. Philadelphia: Temple University Press.

Hale, T. W. 2001. The lack of a disability measure in today's Current Population Survey. *Monthly Labor Review*, 124(6).

Hartman-Squire, Tari Susan, and Mary Johnson. 1994. *Making news: How to get news coverage for disability rights issues*. Louisville, KY: Advocado Press.

King, R.B. and T.E. Backer. 1989. *Overcoming challenges: A guide to selective job placement of workers with disabilities*. Los Angeles: National Medical Enterprises.

Kurzweil, Ray. 2005. *The singularity is near: When humans transcend biology*. New York: Viking.

LaPlante, M. 1988. *Data on disability from the National Health Interview Survey, 1983-1985*. Washington, DC: National Institute for Disability and Rehabilitation Research.

Levitan, Sar A. and Robert Taggart. 1977. *Jobs for the disabled*. Baltimore: Johns Hopkins University Press.

Lynch, Kevin. 1960. *The image of the city*. Cambridge, MA: MIT Press.

Mashaw, J. and V.P. Reno, eds. 1996. *Balancing security and opportunity: The challenge of disability income policy*. Washington, DC: National Academy of Social Insurance.

O'Brien, Ruth. 2001. *Crippled justice: The history of modern disability policy in the workplace*. Chicago: University of Chicago Press.

———. *Bodies in Revolt: Gender, Disability and the Workplace*. New York: Routledge, 2005.

Oliver, Michael. 1996. *Understanding disability: From theory to practice*. New York: St. Martin's Press.

Shapiro, Joseph P. 1993. *No pity: People with disabilities forging a new civil rights movement*. New York: Times Books.

Siperstein, Gary N., Neil Roman, Amanda Mohler, and Robin Parker. 2006. A national survey of consumer attitudes towards companies that hire people with disabilities. *Journal of Vocational Rehabilitation*, Vol. 24 Issue 1.

Spechler, Jay W. 1996. *Reasonable accommodation: Profitable compliance with the Americans with Disabilities Act*. Delray Beach, FL: St. Lucie Press.

Stapleton, David C. and Richard V. Burkhauser, eds. 2003. *The decline in employment of people with disabilities: A policy puzzle*. Kalamazoo, MI: W.E. Upjohn Institute for Employment Research.

Stern, S. 2003. *Counting people with disabilities: How survey methodology influences estimates in Census 2000 and the Census 2000 supplementary survey*. Census Bureau Staff Research Report. Washington DC: U.S. Census Bureau, Poverty and Health Statistics Branch.

Stone, Deborah. 1986. *The disabled state*. Philadelphia: Temple University Press.

Szymanski, Edna Mora and Randall M. Parker, eds. 2003. *Work and disability: Issues and strategies in career development and job placement*, second edition. Austin, TX: Pro-Ed.

Thomason, Terry, John F. Burton, Jr., and Douglas E. Hyatt, eds. 1998. *New approaches to disability in the workplace*. Madison, WI: Industrial Relations Research Association.

Weaver, Carolyn L., ed. 1991. *Disability and work: Incentives, rights, and opportunities*. Washington, DC: American Enterprise Institute Press.

Yelin, Edward. 1992. *Disability and the displaced worker*. New Brunswick, N.J.: Rutgers University Press.

