

Appendix A: Review of Societal Indicator Systems

Appendix A provides additional information about the indicator systems discussed in Chapter 3. It provides a short description of each initiative and highlights specific indicators that could be considered in measuring the well-being of people with disabilities.

We describe the following social indicator systems:

- Canada’s Performance Reports;
- Canada’s Quality of Life Indicators Project;
- National Organization on Disability Key Indicators;
- *Healthy People 2010* from the Centers for Disease Control and Prevention;
- Older Americans: Key Indicators of Well-Being—Federal Interagency Forum on Aging-Related Statistics
- The State of Black America;
- America’s Children, Federal Interagency Forum on Child and Family Statistics;
- Kids Count, Annie E. Casey Foundation
- Disability Adjusted Life Years, World Health Organization.

1. Canada’s Social Indicator Systems

Canada’s Performance Reports, Treasury Board of Canada: For the past six years, the Treasury Board of Canada has published annual performance reports designed to provide a “whole-of-government view of how individual departments and agencies contribute to broad outcomes in four areas: 1) economic, 2) social, 3) international, and 4) government affairs” (Treasury Board of Canada 2006). It is designed as a companion document to the 88 separate Departmental Performance Reports, which links each indicator with the departments that can impact it.

The economic affairs indicators are: 1) income security and employment for Canadians (employment rate, disposable income); 2) strong economic growth (measures of real gross domestic product, cost competitiveness, natural resource sustainability, and green economic practices); 3) an innovative and knowledge-based economy (measures of GDP spent on research, educational attainment, literacy); 4) a clean and healthy environment (measures of air quality, water use, biodiversity, greenhouse gas emissions); and 5) a fair and secure marketplace (regulatory barriers to entrepreneurship).

The social affairs indicators are: 1) healthy Canadians (measures of life expectancy, self rated health status, healthy lifestyles waiting times, patient satisfaction); 2) safe and secure communities (crime rate, housing needs); 3) a diverse society that promotes linguistic duality and social inclusion (attitudes toward diversity, attitudes toward linguistic duality, volunteerism, political participation); and 4) a vibrant Canadian culture and heritage (participation in cultural and heritage activities).

Canadian Policy Research Network (CPRN) Quality of Life Indicators: While the Treasury Board developed its indicators, a coalition of public, private and not-for-profit organizations led by the Canadian Policy Research Network (CPRN) developed a set of indicators designed to track Canada's progress in improving quality of life and enable broad-based discussion of Canada's condition. The project was driven by input from citizens and indicator experts, with advice provided by a Steering Committee representing diverse interests.

In fall 2000, 350 Canadian citizens met in 40 small groups in locations across the country. Each group deliberated for three hours on what is important for quality of life and on the information they need to assess progress. The nine themes identified here mirror their choices and order of priority. Experts then helped to identify indicators for each of the themes and a group of the original citizen-participants reviewed the indicators (Atkinson Charitable Foundation 2007). The themes and measures are shown in Exhibit A.1.

**Exhibit A.1: Themes and Measures from Canadian Policy Research Network
Quality of Life Indicators**

Living Standards	Secure and meaningful employment, adequate income, low-income rates, gap between rich and poor, food security, and affordable housing
Time Allocation	Balance between paid work, unpaid work, and free time, the capacity to make choices about the use of time, and the stress of overload
Healthy Populations	Self-rated health, disability-adjusted life expectancy (includes cancer, cardiovascular disease), physical health conditions such as low birth weight, asthma, obesity, and diabetes, rates of depression, functional health (injuries), smoking, physical activity, and overall satisfaction with health care services
Ecosystem Health	Good air and water quality, healthy forests, soils, marine environment, greenhouse gas emissions, waste diversion, and environmental sustainability
Educated Populace	Literacy, numeracy, indicators of educational attainment, and quality of formal and informal learning
Community Vitality	Safe communities, cohesion, trust in people, sense of belonging and identity, social networks and social participation, diversity and inclusion, community stability, and access to community resources and services
Civic Engagement	Individual and collective actions designed to identify and address issues of public concern, involvement in extra-familial activities conducted for the purpose of improving the quality of life

2. National Organization on Disability (N.O.D.)

N.O.D. in cooperation with the Harris Poll, has conducted five surveys between 1986 and 2004 to measure the participation of people with disabilities in American life. The survey asks dozens of questions, many of which change each time the survey is administered. From the survey, N.O.D./Harris developed 10 “key indicators” that are monitored over time. These indicators touch on many of the issues identified in our focus groups. After each administration of the survey, N.O.D. releases a report that displays the value of the indicator over time both for people with disabilities and the gap between the value for people with disabilities and those without disabilities (Exhibit A.2).

The size of the survey is problematic. With a sample in the range of 1,000 people with disabilities and 1,000 without, the margin of error for each indicator is roughly plus or minus three percentage points. (See discussion of measurement error in Section III). When we see small changes in the value of the indicator, it is difficult to distinguish between a real change and a measurement error. However, we would generally expect to see either stability over time or a one-directional trend. An indicator that fluctuates over time for no apparent reason may point to a problem with the validity or reliability of the measure. Of course there may be some fluctuations, such as changes in indicators in response to the business cycle, natural disaster, or war, which are expected.

The indicators have several limitations, in addition to the size of the survey population, that are indicative of the type of limitations in many systems. For example, the measure “annual household income of \$15,000 or less” is not adjusted for inflation. This value will decrease over time with no actual change in circumstances. Looking at the percentage point gap between people with and without disabilities is more instructive.

Among people with disabilities, the measure “socializing with friends, relatives or neighbors at least twice a month” has remained relatively constant. The gap has decreased because people without disabilities are socializing less. This is an example where a reduction in the gap is not a positive sign.

The N.O.D. statistic on percent of respondents that have graduated from high school is not very responsive to actual changes in the high school graduation rate. This indicator includes respondents of all ages, but only a small portion of the population (adolescents and young adults) is affected by policies and attitudes that might increase the graduation rate of people with disabilities. Thus, even a significant change in graduation rates would not show up in the indicator for many years.

Exhibit A.2: National Organization on Disability/Harris Survey—Key Indicators—

Trends for people with disabilities and gaps between people with and without disabilities, 1986–2004

Indicators	Percent of People with Disabilities					Percentage Point Gap Between People With and Without Disabilities				
	2004	2000	1998	1994	1986	2004	2000	1998	1994	1986
Employment—Works either full or part-time (ages 18-64)	35	32	29	31	34	43	49	50	n/a	n/a
Income—Annual household income \$15,000 or less	26	29	34	40	51	17	19	22	22	22
Education—Has not graduated from high school	21	22	20	24	39	10	13	11	12	24
Health Care—Did not get needed care on at least one occasion in the past year	18	19	21	18	n/a	11	13	10	5	n/a
Transportation—Inadequate transportation considered a problem	30	30	30	n/a	n/a	17	20	13	n/a	n/a
Socializing—Socializes with close friends, relatives, or neighbors at least twice a month	79	81	82	81	n/a	10	15	15	18	n/a

(continued)

Exhibit A.2: National Organization on Disability/Harris Survey—Key Indicators—

Trends for people with disabilities and gaps between people with and without disabilities, 1986–2004 (cont.)

Indicators	Percent of People with Disabilities					Percentage Point Gap Between People With and Without Disabilities				
Going to Restaurants—Goes to a restaurant at least twice a month	56	56	51	50	48	16	19	27	21	24
Attendance at Religious Services—Goes to church, synagogue, or any other place of worship at least once a month	49	47	54	48	55	8	18	3	10	11
Political Participation—Voter turnout in the presidential election*	52	41	33	45	n/a	4	11	17	11	n/a
Satisfaction with Life—Very satisfied with life in general	34	33	33	35	39	27	34	28	20	11
Number of Respondents with Disabilities	1,267	997	989	1,003	981					

Source: Harris Interactive 2004

n/a is “not available”

* 1998 data refers to the 1996 election, 1994 data refers to the 1992 election

3. *Healthy People 2010*

Office of Disease Prevention and Health Promotion, Department of Health and Human Services (<http://www.healthypeople.gov/>).

Healthy People 2010 is a set of disease prevention and health promotion objectives for the nation to achieve over the first decade of the new century. It is designed to focus public and private sector efforts to address threats to health by providing information and knowledge about how to improve health in a format that is accessible to diverse groups, including states and communities, professional organizations, and other groups.

The 28 focus areas of *Healthy People 2010* were developed by Federal agencies, with the relevant scientific expertise. The development process was informed by the Healthy People Consortium—an alliance of more than 350 national membership organizations and 250 state health, mental health, substance abuse, and environmental agencies. Additionally, through a series of regional and national meetings and an interactive web site, more than 11,000 public comments on the draft objectives were received. The Secretary's Council on National Health Promotion and Disease Prevention Objectives for 2010 also provided leadership and advice in the development of national health objectives.

Among the hundreds of objectives listed in *Healthy People 2010*, an interagency work group within the U.S. Department of Health and Human Services assisted by others chose the following 10 “leading health indicators”: 1) Physical Activity; 2) Overweight and Obesity; 3) Tobacco Use; 4) Substance Abuse; 5) Responsible Sexual Behavior; 6) Mental Health; 7) Injury and Violence; 8) Environmental Quality; 9) Immunization; and, 10) Access to Health Care.

The Leading Health Indicators were selected on the basis of their ability to motivate action, the availability of data to measure progress, and their importance as public health issues. Of the 21 measures used to monitor the 10 indicators, fewer than half are based on data sources that identify the disability status of the respondents. This is due in large part to the absence of disability status indicators in the National Vital Statistics

System (Natality and Mortality), the National Survey on Drug Use and Health, and the Youth Risk Behavioral Surveillance Surveys. Because equivalent data is not available from other sources that do identify disability status, many indicators cannot be monitored for people with disabilities using existing data.

Although many of the leading indicators cannot be measured for people with disabilities, one of the focus areas (focus area six) is devoted to “Disability and Secondary Conditions.” It consists of 13 goals—many of which coincide with the quality of life objectives identified by our focus groups. The indicators, along with data where available, are shown in Exhibit A.3.

Exhibit A.3: *Healthy People 2010*. Selected Focus Area Six Indicators 1997–2005

Objective	1997	2000	2002	2003	2005	Target 2010
6-1 Include in the core of all relevant <i>Healthy People 2010</i> surveillance instruments a standardized set of questions that identify "people with disabilities"						
6-2 Reduce the proportion of children and adolescents with disabilities who are reported to be sad, unhappy, or depressed						
6-3 Negative feelings interfering with activities among adults with disabilities (age adjusted, aged 18 years and over)	28%	29%	30%	32%	32%	7%
6-4 Social participation among adults with disabilities (age adjusted, aged 18 years and over)			—	—	—	79%

(continued)

**Exhibit A.3: *Healthy People 2010*. Selected Focus Area Six Indicators
1997–2005 (cont.)**

Objective	1997	2000	2002	2003	2005	Target 2010
6-5 Sufficient emotional support among adults with disabilities (50 States and D.C., age adjusted, aged 18 years and over)					67%	80%
6-6 Satisfaction with life among adults with disabilities (50 States and D.C., age adjusted, aged 18 years and over)					84%	97%
6-7a Congregate care of adults with disabilities (number, aged 22 years and over)	93,362	82,582	77,085	70,596	65,575	46,681
6-7b Congregate care of children and young adults with disabilities (number, aged 21 years and under)	26,028	—	—	—	26,395	0
6-8 Employment rate of adults with disabilities equivalent to adults without disabilities—Adults with disabilities (aged 18 to 64 years)	43%	44%	42%	41%	40%	80%
6-9 Inclusion of children and youth with disabilities in regular education programs (aged 6 to 21 years)	45%	47%	48%	48%	54%	60%
6-10 Access to health and wellness programs among persons with disabilities (age adjusted, aged 18 years and over)			48%	—	—	63%

(continued)

**Exhibit A.3: *Healthy People 2010*. Selected Focus Area Six Indicators
1997–2005 (cont.)**

Objective	1997	2000	2002	2003	2005	Target 2010
6-11 Not having assistive devices and technology among persons with disabilities (age adjusted, aged 18 years and over)			10%	—	—	7%
6-12 Environmental barriers affecting participation among persons with disabilities (age adjusted, aged 18 years and over) in the following locations:						
a. at home			10%	—	—	9%
b. at school			6%	—	—	6%
c. at work			8%	—	—	7%
d. in community activities			11%	—	—	7%
6-13 Increase the number of Tribes, States, and the District of Columbia that have public health surveillance and health promotion programs for people with disabilities and caregivers.						

Source: *Healthy People 2010*.

4. Older Americans: Key Indicators of Well-Being

Federal Interagency Forum on Aging-Related Statistics (<http://www.agingstats.gov/>).

The interagency forum is a coalition of 13 Federal agencies that produce or use statistics on aging (National Institute on Aging, National Center for Health Statistics and Census Bureau, Administration on Aging, Agency for Healthcare Research and Quality, Bureau of Labor Statistics, Centers for Medicare and Medicaid Services, Department of Veterans Affairs, Environmental Protection Agency, Office of Management and Budget, Office of the Assistant Secretary for Planning and Evaluation in HHS, Social Security Administration, and the Substance Abuse and Mental Health Services Administration). The forum has developed 37 key indicators about older Americans, categorized into five broad groups: population, economics, health status, health risks and behaviors, and health care. The indicators are shown in Exhibit A.4.

Exhibit A.4: Older Americans Key Indicators of Well-Being

Population	Health Risks and Behaviors
<ul style="list-style-type: none"> 1. Number of Older Americans 2. Racial and Ethnic Composition 3. Marital Status 4. Educational Attainment 5. Living Arrangements 6. Older Veterans 	<ul style="list-style-type: none"> 21. Vaccinations 22. Mammography 23. Dietary Quality 24. Physical Activity 25. Obesity 26. Cigarette Smoking 27. Air Quality
<p>Economics</p> <ul style="list-style-type: none"> 7. Poverty 8. Income Distribution 9. Sources of Income 10. Net Worth 11. Participation in the Labor Force 12. Housing Expenditures 	<p>Health Care</p> <ul style="list-style-type: none"> 28. Use of Health Care Services 29. Health Care Expenditures 30. Prescription Drugs 31. Sources of Health Insurance 32. Out-of-Pocket Health Care Expenditures
<p>Health Status</p> <ul style="list-style-type: none"> 13. Life Expectancy 14. Mortality 15. Chronic Health Conditions 16. Sensory Impairments and Oral Health 17. Memory Impairment 18. Depressive Symptoms 19. Disability 20. Respondent Assessed Health Status 	<ul style="list-style-type: none"> 33. Sources of Payment for Health Care Services 34. Veterans Health Care 35. Nursing Home Utilization 36. Residential Services 37. Caregiving and Assistive Devices

Source: Federal Interagency Forum on Aging-Related Statistics.

In each of three years (2000, 2004, and 2006) the forum has produced a chartbook and a web site with the values of each indicator in that year and over time when available. The chartbooks range in length from 75 to 125 pages.

The goal of the endeavor was to “stimulate discussions by policymakers and the public, encourage exchanges between the data and policy communities, and foster improvements in Federal data collection on older Americans. By examining a broad range of indicators, researchers, policymakers, service providers, and the Federal government can better understand the areas of well-being that are improving for older Americans and the areas of well-being that require more attention and effort.” (Federal Interagency Forum on Aging-Related Statistics 2000).

The measures are drawn from 15 data collection instruments—regularly administered government surveys or ongoing data collection efforts.¹

The Forum identified several areas where more data is needed to support research and policy efforts also relevant to the disability population: gathering information on minorities; improving measures of disability, including the institutional population in national surveys; gathering national statistics on abuse; improving the way data are collected to measure both income and wealth; and gathering information on the impact of transportation needs on the quality of life (Federal Interagency Forum on Aging-Related Statistics 2000).

5. *America’s Children*

Federal Interagency Forum on Child and Family Statistics (<http://www.childstats.gov/>).

Each year since 1997, the Federal Interagency Forum on Child and Family Statistics has published *America’s Children: Key National Indicators of Well-Being*, a report that includes detailed information on the well-being of children and families. Like the Forum on Aging-Related Statistics, the Forum on Child and Family Statistics is a coalition of government agencies. Each year it posts new data on its website, and alternates publishing the more detailed report with a condensed version that highlights selected indicators.

¹ Consumer Expenditure Survey, CPS, Decennial Census, EPA administrative data, Health and Retirement Survey, Medicare administrative data, Medicare Current Beneficiary Survey, MEPS, NHANES, NHIS, National Long-Term Care Survey, National Nursing Home Survey, Panel Study of Income Dynamics Veterans Health administrative data, and Vital Statistics

In addition to the overall tables, the chartbook includes tabulations by race, poverty status, region, and other demographic characteristics. It does not include tabulations by disability status. This may not be surprising given the difficulty in defining and measuring disability among children, especially young children. (See Simeonsson 2006 for a discussion of the difficulty.) The indicators rely heavily on the CPS, vital statistics, and other surveys which do not include indicators of disability among children.

Most of the indicators are relevant only to children or included in other indicator systems, so we do not review them here. Rather, we include this indicator set to highlight the value of the interagency collaboration.

6. Kids Count

Annie E. Casey Foundation (<http://www.aecf.org/kidscount/>).

Kids Count, a project of the Annie E. Casey Foundation, is a national and state-by-state effort to track the status of children in the U.S. by providing policymakers and citizens with benchmarks of child well-being. For the past 16 years, Kids Count has produced a data book and in more recent years, a website that presents the data. Kids Count is not focused on disability nor does it include indicators that were identified by our focus groups. We include it in our discussion because the Casey Foundation has established a process that brings together data from disparate sources and effectively disseminates the information. For example, the release of the 2005 *Kids Count Data Book* resulted in 981 known print stories, 560 televised stories, and many radio broadcasts. The Foundation produced and distributed 65,000 copies of *Data Book* and distributed them to, among others, state and local leaders and members of Congress (Hager Sharp 2005). Many of the dissemination and public awareness activities are performed by Casey Foundation Supports Kids Count projects in 50 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands.

The *Kids Count* project includes over 75 measures of child well-being from about 10 different data sources, available through their web site. They chose ten measures which reflect important areas of child well-being, reflect experience from birth through early

adulthood, and are available from existing data sources consistently over time and across states, including:

- percent low birth-weight babies;
- infant mortality rate;
- child death rate;
- rate of teen deaths by accident, homicide, and suicide;
- teen birth rate;
- percent of children living with parents who do not have full-time, year-round employment;
- percent of teens who are high school dropouts;
- percent of teens not attending school and not working;
- percent of children in poverty;
- percent of families with children headed by a single-parent.

7. *State of Black America*

The National Urban League annually publishes *The State of Black America*, which includes an “Equality Index.” The Index, developed by Global Insight, Inc., is a compilation of many data elements into a single number that provides a statistical measurement of the disparities or “equality gaps” that exist between African-Americans and whites across five different “sub-indices”: economics, education, health, civic engagement and social justice. In 2007, the Index put the status of African-Americans with respect to whites at 73.3 percent.

Global Insight uses a statistical approach to compute a value for each sub-index and overall index. NUL provides little information about the details of the approach but highlights that the calculations are weighted to reflect the “relative importance” of each

group of data. Economics is weighted at 30% followed by health (25%), education (25%), social justice (10%) and civic engagement (10%).

Each sub-index is divided into categories and each category contains between one and twenty data elements. For example, as shown in Exhibit A.5 below, the economics sub-index is divided into five separate categories: housing and wealth formation, median income, employment issues, poverty, transportation and the digital divide. A value is computed for each sub-index based on the weights assigned to each category and data element.

Exhibit A.5: Categories and Data Elements in the Economics Sub-index of the National Urban League Equality Index

Economics Sub-Index—30% of Equality Index	
Category and Data Elements	% of Economics Index
Housing and Wealth Formation	34%
Mortgage Application Denial rate	8%
Home Improvement Loans Denial rate	8%
Home Ownership rate	1%
Median Home Values	1%
Median Net Worth	8%
Equity in Home	8%
Percent of people investing in 401K	1%
Median Income	25%
Median Male Earnings by Highest Degree Earned	8%
Median Female Earnings by Highest Degree Earned	8%
Median Income	8%
Employment Issues	20%
Unemployment rates (overall and for person 16-19)	10%
Labor Force participation rate by age and educational attainment	9%
Employment to population ratio	1%
Poverty	15%
Percent of the population living below the poverty line	9%
Percent living below 50% of the poverty line	1%
Percent living below 125% of the poverty line	5%

(continued)

Exhibit A.5: Categories and Data Elements in the Economics Sub-index of the National Urban League Equality Index

Economics Sub-Index—30% of Equality Index	
Category and Data Elements	% of Economics Index
Digital divide Percent of households with computer at home Percent of households using the Internet Percent of households with broadband access	5%
Transportation Car ownership Drive alone Reliance on public transportation	1%

Source: National Urban League 2007

The strength of the index is that it summarizes a great deal of data into a single figure that can be used to track changes over time. Based on the frequency that the value is reported, it is very appealing for advocacy organizations and news broadcasts. In addition, the approach allows the reader to “drill down” to the individual statistics to understand what is driving the overall number.

The major limitation of the index is that the value is based in large part on value judgments about the relative importance of different factors. Who made these judgments? Would most people agree with the judgments? For example, can we all agree that the economics sub-index was more important than health? Or that within the economics sub-index, housing and wealth formation (which focuses on home ownership), was more important than median income or employment? Different decisions about the weights would yield a different value for the indicator.

The index offers two lessons for this project. First, the publication identifies indicators and sources used to measure equality for African-Americans that may be relevant for measuring the social well-being and “equality” of people with disabilities. A thorough

review of the data sources used revealed that with the exception of the American Community Survey, most of the data sources used include either an inadequate disability indicator (such as the Current Population Survey) or have no disability indicators at all (such as the Bureau of Labor Statistics, the Home Loan Disclosure Act data, the Survey of Consumer Finances, CDC's vital statistics systems, the Bureau of Justice statistics). Second, it highlights the complexity and value judgments inherent in creating a single index from relatively unrelated data elements.

8. Disability Adjusted Life Years and Quality Adjusted Life Years

World Health Organization

There are two well-known quality of life composite indicators, Disability Adjusted Life Years (DALYs) and Quality Adjusted Life Years (QALYs). These indicators are constructed by summing the years lost due to premature mortality with the loss experienced by living a certain number of years with a disability. There are several glaring problems with DALYs and QALYs. First, they are based completely on the medical model, where disability is viewed as a medical condition that rests within the individual. Second, they devalue the lives of people with disabilities. A year lived with a disability is counted as something less than a year lived without one. Conversely, saving the life of a disabled person does not improve the summary measure of health as much as saving the life of a non-disabled person. Third, they do not take into account the role of the environment in mitigating the functional impact of a medical impairment. As a result, if a program improves the well-being or quality of life for a person with a disability but they retain their impairment, these indicators show no improvement. We mention these as a way to illustrate what to avoid in creating quality of life indicators and note that disability-adjusted life expectancy is being considered by the coalition developing Canada's Index of Well-being.

Appendix B: Background and Methodology for Focus Groups

1. Background

Two groundbreaking documents were critical to our design of the focus groups and our thinking about quality indicators. We used these documents to familiarize ourselves with other efforts to obtain consumer input into the development of quality indicators and to inform our moderator's guide. These documents are summarized briefly below.

A. Asking Citizens What Matters for Quality of Life in Canada: The Canadian Quality of Life Indicators Project used a citizen involvement process to develop a prototype of national quality of life indicators. The Canadian Policy Research Networks (CPRN) conducted 40 dialogue groups in which participants discussed quality of life in Canada. They recruited quasi-random samples of urban and rural participants and purposive samples consisting of urban and rural “influencers,” hard to reach participants including people with disabilities, and youth. Participants were also given questionnaires before and after the discussions.

CPRN used the information gathered from the discussions and the questionnaires to form a table with 17 Quality of Life themes and sub-themes. They found a number of national indicator priorities across all groups: health care access including physical or mental health, primary and secondary education, the environment, clean air and water, social programs including income supports and housing for vulnerable populations, political rights, responsible taxation, job security, employment opportunities, a living wage, time use or balance, public safety and security, civic participation, and children and youth programs. There were also overarching or cross-cutting themes that permeated the discussions, such as access, availability, personal security, and equity and fairness. They felt that health care, the environment, education, and social programs were areas in need of improvement and should be monitored more systematically. Participants had difficulty suggesting what indicators should be used to monitor programs, and felt comfortable relying on “experts” to develop such indicators.

B. Livable Communities for Adults with Disabilities: The Livable Communities for Adults with Disabilities Report (NCD 2004) describes the factors that support livable communities for people with disabilities and older adults. These factors include (1) the elements of a livable community, (2) existing examples of livable communities in the United States, and (3) how these communities develop and sustain livability features.

We were particularly interested in the elements of a livable community and the process by which NCD obtained perspectives from people with disabilities. NCD defines a “livable community” as one that contains elements that make the community desirable for individuals with disabilities and older Americans, but makes the point that these elements make the community more livable for others as well. According to NCD, the framework was based upon a similar framework developed for the AdvantAge Initiative, that helps communities measure and improve their “elder-friendliness,” as well as research on the concept of livability, recent surveys of people with disabilities, countless interviews with key informants, and a focus group in Washington, DC. The report defines a livable community for adults with disabilities as one that achieves the following:

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

Within each of these areas, a livable community strives to maximize independence, assure safety and security, promote inclusiveness, and provide choice (NCD 2004, p. 8).

2. Methodology²

We conducted a series of seven focus groups to obtain input from a variety of stakeholders; six focus groups with persons with disabilities and their advocates and one focus group of service providers. These included three cross-disability groups of people with disabilities: one in St. Louis, one in Washington, DC, and one with members of the American Association of People with Disabilities (AAPD) by tele-conference. (The AAPD group was actually conducted in two smaller groups.) We conducted one group of people with psychiatric disabilities in Northern Virginia with participants in the Laurie Mitchell Employment Center (LMEC); and one with members of the Consortium for Citizens with Disabilities (CCD) and other advocates in Washington, DC. We conducted the service providers group in St. Louis, Missouri.

A. Recruiting participants and organizing the focus groups: Potential participants may decline to participate when contacted by researchers because they have a mistrust of research, do not want to disclose their experiences to people outside of their neighborhood or culture, or may not want to participate in a research project with an organization that is unknown to them. Therefore, we worked with organizations of people with disabilities we wished to recruit to identify participants and host the focus groups. We used the following organizations to recruit our focus groups:

- People with disabilities and service providers in St. Louis: David Gray, our steering committee member, and Paraquad, the Center for Independent Living in St. Louis³
- People with disabilities in the Washington, DC area: Help Yourself, Inc., an advocacy group in Washington, DC
- National teleconference of people with disabilities: American Association of People with Disabilities (AAPD)

² This project was reviewed and approved by the Cornell University Institutional Review Board (IRB) on October 3, 2006 as required.

³ Paraquad serves individuals with all types of disabilities, not just those with mobility impairments.

- People with psychiatric disabilities: Laurie Mitchell Employment Center (LMEC)
- National disability advocates: Consortium for Citizens with Disabilities (CCD)

We developed a brief guide that outlined the responsibilities and requirements for coordinating the focus groups. We modified each guide slightly to target each group we wanted to recruit. The guide covered the following topics: purpose of the focus groups, recruiting and screening participants, confidentiality, logistics including accessibility, and payment of focus group members and coordinators.

The recruitment criteria for participation in the focus groups included:

- Individuals must face significant barriers to full participation in society, such as employment, obtaining health care, using public transportation, or having social relationships, or, in the case of service providers or advocates, must serve or advocate on behalf of such individuals
- Focus group participants must represent a variety of disabilities, including physical, learning, intellectual, psychiatric, and sensory
- Focus group participants must represent a variety of ethnic and socioeconomic backgrounds.

Coordinators recruited between ten and twelve individuals per focus group, with a target participation of eight to ten persons. This strategy enabled adequate participation if some members dropped out due to illness, lack of transportation, day care problems, etc. (We were unable to arrange a convenient time for all of the AAPD group members to participate, so we conducted two small groups.) We paid each coordinating agency \$75 for each participant they recruited and for expenses, such as transportation, sign language interpreters, or light snacks.

A representative of the coordinating agency contacted potential participants by telephone to explain the topic of the focus group to them and describe how a focus group is conducted. They administered a brief screening instrument, contained in Appendix B.1,

asking potential participants to describe their disability and other demographic data. This data enabled us to ensure that a wide variety of perspectives and socioeconomic characteristics are represented and to enable us to describe our participants. Social service provider representatives provided information about their position and agency. After conducting the first three focus groups, we realized that the perspectives of people with psychiatric disabilities were not being represented; therefore we approached the LMEC to assist with one of our focus groups. Participants in the consumer and advocacy groups received a \$75 gift certificate plus reimbursement for transportation, childcare, or other expenses they incurred while participating in the focus groups.

B. Moderator's guide: We developed a moderator's guide (Appendix B.2) containing an introductory script, followed by broad questions and several probes. We based our questions on the Livable Communities for Adults with Disabilities Report (NCD 2005) and added domains from Asking Citizens What Matters for Quality of Life in Canada (Michalski 2001), as described in Section 2 of this report. The probes helped to focus the discussion, move it forward when it got "stuck," and insured that all relevant topics were covered. The probes were used extensively in some groups and less so in others, depending upon the flow of the discussion.

C. Conducting the focus groups: Before conducting the focus groups, we reviewed the completed screening instruments provided by staff of the coordinating agency, to make sure we had diversity in our focus groups and to briefly acquaint us with the focus group participants. The screeners also provided information as to the types of accommodations needed to make the focus groups accessible; e.g., Braille materials, sign language interpreters, personal assistants.

We used three staff in each focus group: one facilitated discussion, the second assisted with discussion and wrote responses on a flip chart, and the third took computerized notes. Focus groups were roughly 90 minutes in length. We began our focus group by briefly explaining the project and what we are seeking from participants in lay language that participants can understand. We distributed and explained the consent form (provided in accessible formats), which describes the voluntary nature of participation

and how we protect member confidentiality. We then explained the “rules” of the group, including respect for what each member has to say, speaking one at a time, speaking with each other rather than just to the moderator, etc.

We began with an opening “Icebreaker” to allow each person to speak, become comfortable talking in the group, and to provide an indication of the daily experience of participants. We then asked an open-ended question to elicit the life domains that are important to participants. We asked this as an open-ended question to get their first reactions as to what is important to them, without feeding them our preconceived categories. We then roughly followed our moderator’s guide, based upon the flow of the group. We changed the order of the domains in some groups to make sure that questions toward the end of the guide received equal attention. We wrote the domains and paraphrased what participants said about what was important on a flip chart. We read the list of domains and indicators frequently for the focus group we conducted by telephone so participants could keep track without seeing them on a flip chart. A research assistant took computerized notes and produced a list of domains and what participants felt indicated quality under each domain.

The group of CCD representatives was conducted somewhat differently. We began with a presentation about the project and a draft table containing domains and cross-cutting dimensions resulting from the focus groups (Tables 4 and 5). We asked for their reactions and feedback on the table. We included their feedback in our final table.

D. Data analysis: The research assistant divided all participant comments into domains that were listed in the focus group moderator’s guide (e.g., employment, housing), and used the notes to categorize comments into other domains not listed in our guide. She then divided all comments into the appropriate domain. Lists were reviewed by the other two project staff and then compiled so that, for example, comments on transportation from all groups appeared in one list. Project staff reviewed these lists to discover common themes or dimensions, such as choice, empowerment, accessibility, inclusion, etc. This was an iterative process, with dimensions added or collapsed based upon our discussions. Finally, we developed a draft table of results,

with examples of each domain/dimension derived from the focus groups, completing the table cells. We reviewed this document with CCD representatives and the steering committee and made suggested changes.

E. Demographics and affiliations of participants: A total of 57 people participated in our seven focus groups, including consumers, advocates and providers. We collected demographic information from each participant, including type of disability, race, income and other socioeconomic characteristics from participants in focus groups of people with disabilities, including the AAPD focus groups. We collected only type of disability served for the service provider and CCD focus groups. The number of participants in each group is shown in Exhibit B.1.

Exhibit B.1: Number of Participants in Each Focus Group

Focus Group	Number in Group
AAPD-1and 2	7
Help Yourself	14
LMEC	10
St. Louis Consumers	10
St. Louis Providers	8
CCD	8
Total	57

Demographics of the consumer focus group participants are shown in Exhibit B.2. We included the AAPD participants as consumers, because they had disabilities and spoke from their own experiences. Because these participants tended to be employed as disability advocates (working for state independent living councils or centers for independent living, for example) and were white, well educated and higher income, their inclusion tended to skew our sample toward these groups. We made additional efforts to insure a more diverse sample in the other consumer groups. Excluding AAPD participants, 40% of focus group participants were non-white; 41% had not graduated from college, and 29% had annual incomes under \$20,000.

Disabilities represented by the service provider and CCD groups are shown in Exhibit B.3. These groups served people with physical, developmental, and sensory disabilities.

Exhibit B.2: Demographics of Consumer Focus Group Participants

Characteristic	Number	Percent
Disability		
Cerebral Palsy	2	5%
Brain Injury	2	5%
Hearing Impairment/Deaf	4	10%
Intellectual Disability	1	2%
Learning Disability	1	2%
Psychiatric Disability	6	15%
Spinal Cord Injury/Disease	7	17%
Visual Impairment/Blind	8	20%
Other	10	24%
No Response	7	12%
Race		
African-American	11	27%
Asian	2	5%
Hispanic	1	2%
White	21	51%
No Response	6	15%
Education Level		
Less than High School graduate	2	5%
High School graduate	4	10%
Vocational or trade school	1	2%
Some College	7	17%
College graduate	11	27%
Some post-graduate work	3	7%
Master's degree	10	24%
PhD or JD	3	7%

(continued)

Exhibit B.2: Demographics of Consumer Focus Group Participants (cont.)

Characteristic	Number	Percent
Income		
Under \$20,000	10	24%
\$20,000-\$39,999	7	17%
\$40,000-\$59,999	3	7%
\$60,000-\$79,999	4	10%
Over \$80,000	8	20%
No Response	9	22%
Total	41	100%

Exhibit B.3: Disability Groups Represented by CCD or Providers

Disability	Number	Percent
Cross Disabilities	4	25%
Blind/Visual Impairment	1	6%
Spinal Cord Injury	1	6%
Deaf/Hard of Hearing	1	6%
Developmental Disabilities	7	44%
Learning Disability	1	6%
Multiple Sclerosis	1	6%
Total	16	100%

Appendix B-1. Telephone Recruitment Form

The purpose of these focus groups is to obtain input from people with disabilities and people who provide services to them about their quality of life and what factors they think would constitute a high quality of life. We will ask you about your satisfaction with several areas of life, including employment, housing, recreation, transportation, and community participation, as well as others you might suggest. This information will help service providers and others who plan programs to improve their programs and make them more responsive to consumer needs. We also hope that we can develop a set of measurements that will enable administrators to measure the quality of their programs.

This project is being sponsored by the National Council on Disability (NCD), an independent federal agency making recommendations to the President and Congress to enhance the quality of life for all Americans with disabilities and their families. NCD is composed of 15 members appointed by the President and confirmed by the U.S. Senate. NCD's overall purpose is to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities, regardless of the nature or severity of the disability; and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society.

All of the information you provide during the focus group or on the screening form will be kept confidential. We will change your name in any reports we write so that no one knows that you participated. We will mail you a self-addressed, stamped envelope and a consent form for you to sign that details the way we keep information confidential.

We are attempting to recruit people with a wide variety of backgrounds for the focus group. We are looking for people who provide services for people of different ages, races, disabilities, educational levels and occupational backgrounds. We would appreciate if you would answer demographic questions on the form below. If you feel uncomfortable with any question, you may just skip it. This will not disqualify you from participation in the focus group.

Telephone Recruitment Form

1. Name: _____

2. Mailing address:

(City)

(State)

(Zip)

3. Telephone number (home): _____

4. Telephone number (work if applicable): _____

5. E-Mail address (if applicable): _____

6. Gender _____

7. What is your age? _____

8. What is your primary disability, impairment, or health condition? _____

9. Do you have any other disabilities, impairments, or health conditions that affect your ability to perform daily activities?

Yes No

If yes, what other disabilities do you have? _____

10. [If applicable] What type of service agency do you work in? _____

What is the population you serve? _____

11. With what racial or ethnic group do you identify? _____

12. Are you currently employed? Yes No

If yes, what is your occupation? _____

13. What is the highest level of education you have completed?

_____ Less than high school

_____ High school graduate

_____ Some college

_____ College graduate

_____ Vocational or trade school

_____ Some post-graduate work

_____ Master's Degree

_____ Other (please specify): _____

14. What is your marital status?

_____ Married

_____ Never married

_____ Widowed

_____ Divorced

15. How many people live in your household, including yourself? _____

16. Please tell us your approximate family income, before taxes, including all sources.

_____ Under \$20,000

_____ \$20,000-\$39,999

_____ \$40,000-\$59,999

_____ \$60,000-\$79,999

_____ Over \$80,000

17. Do you need any accommodations to participate in a telephone focus group? If so, please explain what you will need. _____

Thank you very much. Please email this questionnaire back to asr45@cornell.edu or return it, along with the consent form in the stamped envelope you have received. We look forward to your participation in the focus group.

Appendix B-2. Moderator's Guide

Introductory Script

Administer written informed consent before the group begins. This will cover note taking, confidentiality, the honorarium, and give people the opportunity to decline to participate if they so choose.

Introduce the facilitators.

The purpose of these focus groups is to obtain input from people with disabilities and people who provide services to them about their quality of life and what factors they think would constitute a high quality of life. We will ask you about your satisfaction with several areas of life, including employment, housing, recreation, transportation, and community participation, as well as others you might suggest. This information will help service providers and others who plan programs to improve their programs and make them more responsive to consumer needs. We also hope that we can develop a set of measurements that will enable administrators to measure the quality of people's lives.

This project is being sponsored by the National Council on Disability (NCD), an independent federal agency making recommendations to the President and Congress to enhance the quality of life for all Americans with disabilities and their families. NCD is composed of 15 members appointed by the President and confirmed by the U.S. Senate. NCD's overall purpose is to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities, regardless of the nature or severity of the disability; and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society.

We'd like your help as people who have disabilities (or work with people who have disabilities) in figuring out how federal programs can be more responsive to your needs.

Before we begin, let me explain a little bit about how a focus group works. [Cover the following topics: confidentiality between focus group members; assign pseudonyms;

encourage conversations with each other—comments do not need to be directed to the facilitator; speak one at a time and to the whole group, etc.]

Do you have any questions before we get started? [Discuss logistics: people should feel free to get up if they need to; location of restrooms]. At the end of the focus group, we will reimburse you for any money you paid for transportation or other costs to participate in this group.

1. Icebreaker: Please introduce yourself and tell us in a minute or two how you would spend a normal weekday and a normal weekend day. For example, do you work, go to school, attend church, get together with friends, or what? [Moderators demonstrate the desired response by briefly introducing themselves.]

2. How would you define a good quality of life for yourself?

PROBE: Think about many aspects of life that are important to you, such as work, relationships, participation in your community, or health.

3. Please name one area of your life that you would like to be different. For example, [moderator gives an example such as, “I would like to have more time for personal relationships outside my job. If I could designate one night a week to get together with friends, I would really feel better.” Ask each person what area they would like to improve.]

PROBE: How would you know when you have reached this goal?

PROBE: What would be the characteristics of the [reiterate goal] when you achieve it?

PROBE: How would your life be different than it is now once this goal is achieved?

If you were working with an agency to achieve this goal, how would you judge whether the agency had really helped you?

PROBE: Are there others of you who think this area is important to them?
[Repeat above probes for each person who so indicates.]

4. The National Council on Disability has asked consumers what they think would provide a livable community and we think what NCD has learned provides a good framework for discussion about what aspects, or areas, of life are important. We've already mentioned some of the ones on NCD's list, and we've added a few ourselves, but there are others we haven't talked about. So I want to ask you what would be a measure of quality of life in each of the areas NCD has identified. The areas are:

- Housing
- Transportation
- Community access and inclusion
- Work and education
- Health care and technology
- Participation in civic, cultural, social, and recreational activities
- Community supports, such as personal assistance
- Social supports, such as friends and family

For each topic ask:

PROBE: What would indicate quality of life in this area?

PROBE: What would be the characteristics of the [reiterate area] when you achieved what you want?

PROBE: What aspects of [area] do you now have that are important to you?

PROBE: What aspects of [area] are lacking?

PROBE: What else is important in this area?

If you were working with an agency to achieve this goal, how would you judge whether the agency had really helped you?

5. Are there any other areas of life we haven't touched on that you think are important?

Thank you.

Appendix C: National Data Collection Instruments

This Appendix includes a description of each data collection instrument mentioned in either Chapter 4 or Appendix D. For each we list the following: Title and acronym; sponsoring agency; website; sample methodology and sample size, definition of disability, and frequency of data collection.

This appendix serves several purposes:

- It highlights the difference in the type of questions on surveys that are used to define disability. Generally, researchers use a combination of questions to identify whether the respondent has a disability.
- It identifies limitations in survey instruments that affect their adequacy for use in monitoring the status of people with disabilities such as small sample sizes, absence of questions to identify disability, or infrequent survey administration.
- It provides the reader with a website address for further information.

The appendix includes a description of the following data collection instruments:

American Community Survey

Behavioral Risk Factor Surveillance Survey

Bureau of Transportation Statistics, Omnibus Household Survey

Communicable Disease Surveillance Systems

Current Population Survey

Health Care Cost and Utilization Project—National Hospital Discharge Surveys

Individuals with Disabilities Education Act Data

Medical Expenditure Panel Survey

National Ambulatory Care Survey

National Assessment of Adult Literacy

National Crime Victimization Survey

National Health and Nutrition Examination Survey

National Health Interview Survey

National Health Interview Survey/Disability

National Longitudinal Transition Survey

National Organization on Disability/Harris

National Postsecondary Student Aid Study

National Survey of Drug Use and Health

National Survey of Education Support Provision to
Students with Disabilities in Post Secondary Education

National Survey of Family Growth

National Transportation Availability Survey

National Vital Statistics System—Mortality and Natality

Pew Research Center for People and the Press Voter Survey

Survey of Income and Program Participation

Survey of State Developmental Disability Directors

National Survey of Recreation and the Environment

Title:	2005 American Community Survey (ACS)
Sponsoring Agency:	U.S. Census Bureau
Website:	http://www.census.gov/acs/www/
Sample Methodology and Sample Size:	In 2005, the ACS began full implementation of a two-stage stratified sample of 3 million addresses. Prior administrations of the survey had much smaller samples designed for testing and development.
Definition of Disability:	<p>2005 ACS definition of disability is based on three questions:</p> <ol style="list-style-type: none"> 1. Does this person have any of the following long-lasting-conditions: <ol style="list-style-type: none"> a. blindness, deafness, or a severe vision or hearing impairment? and b. a condition that substantially limits one or more basic physical activities such as walking, climbing stairs, reaching, lifting, or carrying? 2. Because of a physical, mental, or emotional condition lasting 6 months or more, does this person have any difficulty in doing any of the following activities: <ol style="list-style-type: none"> a. learning, remembering, or concentrating? and b. dressing, bathing, or getting around inside the home? 3. Because of a physical, mental, or emotional condition lasting 6 months or more, does this person have any difficulty in doing any of the following activities: <ol style="list-style-type: none"> a. going outside the home alone to shop or visit a doctor's office? b. working at a job or business?
Frequency:	<p>Annual</p> <p>There are some limitations in comparing data across years:</p> <ol style="list-style-type: none"> 1. The ACS may revise their disability questions in 2008. 2. Comparison to years prior to 2005 are not possible due to changes in sampling procedures.

Title:	American Housing Survey (AHS)
Sponsoring Agency:	Sponsored by: U.S. Department of Housing and Urban Development Conducted by: U.S. Census Bureau
Website:	http://www.census.gov/hhes/www/housing/ahs/ahs.html
Sample Methodology and Sample Size:	2005 national survey is a sample of about 56,650 interviews conducted every other year weighted based on Census 2000.
Definition of Disability:	The survey queries about physical disabilities but does not include identifiers for any other types of disabilities. HUD has combined the physical disability question with a question about SSI to create a disability indicator that is applicable to the very low income population but other disability populations cannot be identified.
Frequency:	Every two years

Title:	American Time Use Survey (ATUS)
Sponsoring Agency:	Department of Labor, Bureau of Labor Statistics
Website:	http://www.bls.gov/tus/
Sample Methodology and Sample Size:	The ATUS sample is drawn from households that have completed their final month of interviews for the Current Population Survey. The sample includes about 21,000 completed interviews in 2003 and 13,500 per year in 2004 and 2005.
Definition of Disability:	ATUS does not have a disability measure but it is linked to the Current Population Survey: “(Do you/Does anyone in this household) have a health problem or disability which prevents (you/them) from working or which limits the kind or amount of work (you/they) can do?”
Frequency:	Annual

Title:	Behavioral Risk Factor Surveillance Survey (BRFSS)
Sponsoring Agency:	Centers for Disease Control and Prevention (CDC)
Website:	http://www.cdc.gov/brfss/
Sample Methodology and Sample Size:	BRFSS questionnaire is comprised of core questions and optional modules. Each year states administer the core questionnaire and have the choice to administer optional modules supported by the CDC. Sample sizes vary, but typically are in the 2,000 to 4,000 range per state.
Definition of Disability:	Beginning in 2001, the core questionnaire has included two questions that identify persons with disabilities: <ul style="list-style-type: none"> • Are you limited in any way in any activities because of physical, mental, or emotional problems? • Do you now have any health problem that requires you to use special equipment, such as a cane, a wheelchair, a special bed, or a special telephone?
Frequency:	Annual

Title:	Bureau of Transportation Statistics, Omnibus Household Survey
Sponsoring Agency:	U.S. Department of Transportation
Website:	http://www.bts.gov/programs/omnibus_surveys/household_survey/
Sample Methodology and Sample Size:	Approximately 1,000 randomly selected telephone households. The data are weighted to allow inferences about the noninstitutionalized population aged 18 years or older.
Definition of Disability:	“Do you have any kind of disability or health impairment?”
Frequency:	Monthly

Title:	Communicable Disease Surveillance Systems HIV/AIDs and Sexually Transmitted Diseases
Sponsoring Agency:	Centers for Disease Control (CDC), The National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP)
Website:	STD surveillance: http://www.cdc.gov/nchstp/dstd/Stats Trends/Stats and Trends.htm HIV/AIDS surveillance: http://www.cdc.gov/hiv/topics/surveillance/resources/reports/index.htm
Sample Methodology and Sample Size:	Based on number of cases reported by state and local health departments and estimates from special monitoring projects and supplemental surveillance projects.
Definition of Disability:	None
Frequency:	Ongoing

Title:	Current Population Survey (CPS)
Sponsoring Agency:	Bureau of Labor Statistics and the Census Bureau
Website:	http://www.census.gov/cps/
Sample Methodology and Sample Size:	<p>The CPS is a multistage stratified sample of households in the U.S. designed to represent the civilian, non-institutional population. In 2005 the CPS sample was 99,000.</p> <p>The CPS is composed of two parts. The basic monthly survey is administered each month. In addition, in many months, a supplement is administered to collect data on a variety of social topics (e.g., income, poverty, health insurance coverage, occupational mobility, food security, school enrollment, voting behavior, etc.).</p> <p>The disability question is included on the March supplement.</p>
Definition of Disability:	<p>“(Do you/Does anyone in this household) have a health problem or disability which prevents (you/them) from working or which limits the kind or amount of work (you/they) can do?”</p> <p>This is a very controversial definition of disability. The Bureau of Labor Statistics (BLS) is exploring the possibility of adding additional disability-related items to the CPS.</p>
Frequency:	Annual

Source: Burkhauser and Houtenville 2006

Title:	Health Care Cost and Utilization Project—National Hospital Discharge Surveys (HCUP-NHDS)
Sponsoring Agency:	National Center for Health Statistics/CDC
Website:	http://www.cdc.gov/nchs/about/major/hdasd/nhdsdes.htm
Sample Methodology and Sample Size:	The NHDS collects data from a sample of approximately 270,000 inpatient records acquired from a national sample of about 500 hospitals.
Definition of Disability:	None
Frequency:	Since 1965, conducted every year.

Title:	Individuals with Disabilities Education Act Data (IDEA data)
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Sponsoring Agency:	U.S. Department of Education, Office of Special Education Programs
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Website:	https://www.ideadata.org/index.html
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Sample Methodology and Sample Size:	States report data for each child covered under the IDEA. Most information is collected by the local school districts.
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Definition of Disability:	Children served under IDEA. The types of disabilities that qualify for IDEA have changed slightly over time and this change is reflected in the data. Although federal law defines who should qualify for IDEA, there is evidence that the criteria are not applied uniformly across different racial and ethnic groups, across states, and over time. (Coutinho et al. 2002; Hosp and Reschley 2003; NCD 2000)
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Frequency:	Annual
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Title:	Medical Expenditure Panel Survey (MEPS)
Sponsoring Agency:	Agency for Healthcare Research and Quality—United States Department of Health and Human Services
Website:	http://www.meps.ahrq.gov/mepsweb/
Sample Methodology and Sample Size:	<p>The MEPS consists of a family of three interrelated surveys: the Household Component, the Medical Provider Component, and the Insurance Component. The Household Component (HC) collects data from a sample of families and individuals in selected communities across the United States, drawn from a nationally representative subsample of roughly 10,500 households that participated in the prior year's National Health Interview Survey (the actual size of the panel changes each year). It consists of an overlapping panel design in which any given sample panel is interviewed a total of five times over 30 months.</p>
Definition of Disability:	<p>The MEPS data includes a variety of questions that can be used to develop a disability indicator. Generally adults are defined as having a disability if they meet one of the following criteria:</p> <ul style="list-style-type: none"> • have limitations in activities of daily living (such as bathing, dressing, or getting around the house), instrumental activities of daily living (such as managing money, using the telephone, preparing meals, or doing laundry), cognitive functioning, or the amount or kind of work they can do; • have some difficulty with physical functioning (such as bending, grasping, climbing stairs, or walking 3 blocks); • use assistive devices; or • have vision or hearing impairments (cannot read newsprint with glasses or contact lenses, if used, or cannot hear most things people say with a hearing aid, if used). <p>For exact definition used for statistics presented in Appendix E, see Iezzoni and O'Day 2006, pp 297-298.</p>
Frequency:	Annual beginning in 1996

Title:	National Ambulatory Care Survey (NACS)
Sponsoring Agency:	National Center for Health Statistics/CDC
Website:	http://www.cdc.gov/nchs/about/major/ahcd/ahcd1.htm
Sample Methodology and Sample Size:	<p>The data includes roughly 25,000 visits to 1,372 nonfederally employed office-based physicians. Physicians in the specialties of anesthesiology, pathology, and radiology are excluded from the survey.</p> <p>Data for a systematic random sample of 30 visits per physician are recorded by the physician or office staff on an encounter form provided for that purpose. Data are obtained on patients' symptoms, physicians' diagnoses, and medications ordered or provided. The survey also provides statistics on the demographic characteristics of patients and services provided, including information on diagnostic procedures, patient management, and planned future treatment.</p>
Definition of Disability:	None
Frequency:	The survey was conducted annually from 1973 to 1981, in 1985, and annually since 1989.

Title:	National Assessment of Adult Literacy (NAAL)
Sponsoring Agency:	National Center for Education Statistics
Website:	http://nces.ed.gov/naal/
Sample Methodology and Sample Size:	In 2003 the sample included a nationally representative sample of 19,000 adults 16 and up, in homes and in prisons.
Definition of Disability:	<p>An individual is identified as having a disability if they respond affirmatively to any of the following questions</p> <ul style="list-style-type: none"> • Do you have any difficulty seeing the words and letters in ordinary newspaper print even when wearing glasses or contact lenses, if you usually wear them? • Do you have any difficulty hearing what is said in a normal conversation with another person even when using a hearing aid, if you usually wear one? • Have you ever been diagnosed or identified as having a learning disability? • Do you have any other health problem, impairment, or disability now that keeps you from participating fully in work, school, housework, or other activities?
Frequency:	1992 and 2003

Title:	National Crime Victimization Survey (NCVS)
Sponsoring Agency:	U.S. Department of Justice, Office of Justice Programs, Bureau of Justice Statistics
Website:	http://www.ojp.usdoj.gov/bjs/cvict.htm#ncvs
Sample Methodology and Sample Size:	National Crime Victimization Survey (NCVS) is the Nation's primary source of information on criminal victimization. Each year, data are obtained from a nationally representative sample of 77,200 households comprising nearly 134,000 persons on the frequency, characteristics and consequences of criminal victimization in the United States.
Definition of Disability:	Beginning in 2006, several questions were added to identify disability including the following: Due to a health condition, impairment, or disability, are you limited in any of the following major life activities? a. Self-care, such as bathing, dressing, or feeding yourself? b. Communicating, such as talking with or listening to other people? c. Learning any new skills or activities? d. Mobility, such as bending, walking, climbing stairs, or carrying something weighing approximately 10 pounds? e. Self-direction, such as making important decisions concerning your health care, education, or career? f. Living independently, such as preparing meals, shopping for groceries and personal items, and doing housework? g. Managing finances, such as keeping track of your money and paying bills?
Frequency:	Ongoing

Title:	National Health and Nutrition Examination Survey (NHANES)
Sponsoring Agency:	National Center for Health Statistics/CDC
Website:	http://www.cdc.gov/nchs/nhanes.htm
Sample Methodology and Sample Size:	<p>Each year approximately 7,000 individuals of all ages are interviewed in their homes; of those interviewed, approximately 5,000 complete the health examination component of the survey. A majority of the health examinations are conducted in mobile examination centers (MECs).</p> <p>The NHANES survey design is a stratified, multistage probability sample of the civilian noninstitutionalized U.S. population.</p>
Definition of Disability:	<p>The NHANES includes detailed information about health and functional status which can be used to create an indicator for disability including limitations in vision, hearing, Activities of Daily Living (ADLs), and instrument Activities of Daily Living (IADLs).</p> <p>The survey also asks about need for assistive devices and work limitations.</p>
Frequency:	Ongoing since 1999. Three other NHANES periods (NHANES I 1971-1975, NHANES II 1976-1980, NHANES III 1988-1994)

Title:	National Health Interview Survey (NHIS)
Sponsoring Agency:	National Center for Health Statistics/CDC
Website:	http://www.cdc.gov/nchs/nhis.htm
Sample Methodology and Sample Size:	<p>The current questionnaire structure includes two general areas: a core section that remains unchanged across years, and various sets of supplemental questions that change annually. The core consists of three general sections: the family core section, which collects demographic and health information on every member of the household; the sample adult section, which randomly selects an adult and collects additional health related information for that adult; and a sample child section, which collects additional health-related information for the randomly selected child. In each family an adult and child are selected for the questionnaire, which is given via household interviews. The interviewed sample for 2005 consisted of 38,509 households, which yielded 98,649 persons in 39,284 families.</p>
Definition of Disability:	<p>The NHIS contains a broad set of data on disability-related topics, including the limitation of functional activities, mental health questions used to measure psychological distress, limitations in sensory ability, and limitations in work ability. The NHIS questionnaire also queries respondents who indicated a limitation to a functional activity about the source or condition of their functional limitation.</p> <p>A respondent is generally considered to have a disability if they meet one of the following criteria:</p> <ul style="list-style-type: none"> • Need help with ADLs, IADLs; • Are limited in the kind or amount of work they can do; • Have a vision or hearing impairment; • Have functional limitations such as difficulty walking, sitting reaching, carrying, etc.; or • Have a mental disability based on a series of questions about feelings. <p>See Harris et al. (2005) for a full discussion.</p>
Frequency:	Continuously since 1957

Title:	National Health Interview Survey/Disability 1994 (NHIS-D)
Sponsoring Agency:	National Center for Health Statistics/CDC
Website:	http://www.cdc.gov/nchs/about/major/nhis_dis/nhis_dis.htm
Sample Methodology and Sample Size:	The 1994 and 1995 NHIS contained supplemental questions on disability, which came to be known as the NHIS-D (sometimes referred to as the Phase 1 and Phase 2 Disability Supplements). Everyone in the NHIS sample was asked to provide additional information on disability in the NHIS-D for Phase 1. Based on this information individuals meeting certain criteria that indicated the presence of a disability received a follow-up survey, called the Disability Followback Survey (also referred to as the Phase 2 disability supplement). Phase 1 had a sample size of 202,560, the Followback Survey had a sample size of 32,788.
Definition of Disability:	The NHIS-D is not limited to one definition of disability; therefore, it will allow analysts from varying programs to combine data items in different ways to meet specific agency or program needs. See Maag (2006) for a full discussion.
Frequency:	Once

Title:	National Longitudinal Transition Survey (NLTS2)
Sponsoring Agency:	Office of Special Education Programs, U.S. Department of Education
Website:	http://www.sri.com/nlts2/
Sample Methodology and Sample Size:	<p>The most recent survey, NLTS2, started in 2001 and will continue over a 10-year period. It includes a nationally representative sample of 9,000 students receiving special education services who were ages 13 to 16 and in at least 7th grade on December 1, 2000.</p> <p>Data collection includes the following:</p> <ul style="list-style-type: none"> • Phone interviews with parents and youth once every two years • Mail survey to school personnel who know the student • Direct assessments • Transcripts
Definition of Disability:	Only students in special education programs were included.
Frequency:	Second time this study has been conducted; study lasts 10 years.

Title:	N.O.D./Harris Survey of Americans with Disabilities
Sponsoring Agency:	National Organization on Disability
Website:	www.N.O.D.org
Sample Methodology and Sample Size:	<p>Representative sample of the continental United States. The 2004 sample includes 1,267 people ages 18 and over with disabilities and 988 people ages 18 and over without disabilities. Those with disabilities include a general cross section of 1,038 people with disabilities, an oversample of 109 respondents who are blind or have vision impairments, and an oversample of 120 who are deaf or have hearing impairments. All of the results were weighted to be representative of the general population ages 18 and over with and without disabilities.</p> <p>The data were weighted to force agreement with independent estimates of the population classified by demographic variables such as sex, age, and race.</p>
Definition of Disability:	<p>Disability was defined using a number of criteria so as to capture a group with a wide range of disabling conditions, functional limitations, and personal circumstances. More specifically, respondents were considered as having a disability if they met any of the following criteria:</p> <ol style="list-style-type: none"> 1. has a health problem or disability that prevents him or her from participating fully in work, school, housework, or other activities; <i>or</i> 2. reports having a physical disability of any kind; a seeing, hearing, or speech impairment; an emotional or mental disability; a learning disability; <i>or</i> 3. considers himself or herself a person with a disability or says that other people would consider him or her to be a person with a disability (Harris Interactive 2004).
Frequency:	1994, 1998, 2000, 2004. Next survey scheduled for 2008.

Title:	National Postsecondary Student Aid Study (NPSAS)
Sponsoring Agency:	U.S. Department of Education, National Center for Education Statistics (NCES)
Website:	http://nces.ed.gov/surveys/npsas/
Sample Methodology and Sample Size:	The design for the NPSAS sample involves selecting a nationally representative sample of postsecondary education institutions and students within those institutions. The 2004 survey included 101,000 students in 1,630 institutions (undergraduate, graduate, and first-professional students enrolled in postsecondary institutions) between July 1, 2003, and April 30, 2004.
Definition of Disability:	A respondent was considered to have a disability if: <ol style="list-style-type: none"> 1. They reported having “long-lasting conditions” such as blindness, deafness, or a severe vision or hearing impairment; or 2. They reported having “a condition that substantially limits one or more basic physical activities, such as walking, climbing stairs, reaching, lifting, or carrying;” or 3. Reported having “any other physical, mental, or emotional condition that has lasted 6 months or more” and also reported having difficulty doing any one of five activities—getting to school, getting around on campus, learning, dressing, or working at a job.
Frequency:	School years: 1986-87, 1989-90, 1992-93, 1995-96, 1999-2000, and 2003-04.

Source: NCES website

Title:	National Survey of Drug Use and Health (NSDUH)
Sponsoring Agency:	Substance Abuse and Mental Health Services Administration (SAMHSA), U.S. Public Health Service, Department of Health and Human Services (DHHS)
Website:	https://nsduhweb.rti.org/
Sample Methodology and Sample Size:	Nationally representative random sample of approximately 70,000 individuals 12 years old and older.
Definition of Disability:	Detailed information about mental health impairments, but no information about other types of disabilities.
Frequency:	Annual

Title:	National Survey of Education Support Provision to Students with Disabilities in Postsecondary Education
Sponsoring Agency:	National Center for the Study of Postsecondary Educational Supports (NCSPEs) at the University of Hawaii at Manoa
Website:	http://www.rrtc.hawaii.edu/documents/products/phase1/037-H01.pdf
Sample Methodology and Sample Size:	Survey of 650 disability support coordinators (DSCs) working in postsecondary institutions.
Definition of Disability:	Not applicable.
Frequency:	Once

Title:	National Survey of Family Growth (NSFG)
Sponsoring Agency:	National Center for Health Statistics/CDC
Website:	http://www.cdc.gov/nchs/nsfg.htm
Sample Methodology and Sample Size:	<p>The survey is based on a sample of the household population of the United States, 15–44 years of age.</p> <p>The 2002 cycle (cycle 6) was based on an area probability sample. In-person interviews were completed with 12,571 respondents 15–44 years of age—7,643 females and 4,928 males.</p> <p>The most recent cycle (Cycle 7) is being conducted as a continuous survey, with interviews being done 48 weeks of every year. Each year of interviewing will be a nationally representative sample, and samples can be accumulated across years. Given the continuous nature of the survey, it is being done in about 33 areas (Primary Sampling Units) per year. By the end of 4 years of interviewing, it will be a national sample based on 108 areas. The first public use data file is expected to be released in late 2009, based on at least 11,000 interviews conducted between June 2006 and December of 2008.</p>
Definition of Disability:	<p>In its 2002 cycle, the NSFG added disability screening questions for the first time. An individual is considered to have a disability if they answer yes to either of the following questions:</p> <ul style="list-style-type: none"> • Are you limited in any way in any activities because of physical, mental, or emotional problems? • Do you now have any health problem that requires you to use special equipment, such as a cane, a wheelchair, a special bed, or a special telephone?
Frequency:	<p>There have been several cycles of the NSFG—the most recent cycle (Cycle 7) is continuous. The 2002 Cycle 6 was conducted once. Cycles 1-5 were conducted in 1973, 1976, 1982, 1988, and 1995.</p>

Title:	National Transportation Availability Survey
Sponsoring Agency:	Bureau of Transportation Statistics
Website:	http://www.bts.gov/programs/omnibus_surveys/targeted_survey/2002_national_transportation_availability_and_use_survey/
Sample Methodology and Sample Size:	<p>NTS implemented a two-staged respondent selection process. At the first stage, also called the "screener" interview phase, the household phone number was dialed and any eligible household member was asked questions pertaining to the household characteristics and whether anyone in the household had a disability. The first stage resulted in selection of a respondent for the second stage, called the "extended" interview phase. At the second stage, the selected respondent verified his disability status and then answered the remaining questions for the survey. The final sample included 5,019 individuals, 2,321 with persons with disabilities and 2,698 without. All ages included; those under 16 had a proxy.</p>
Definition of Disability:	<p>The disability questions were taken from the Census 2000 long form, as well as from the Americans with Disabilities Act language, with a question on special education. The Freedom to Travel report uses the Census 2000 definition of disability. Thus, an individual is considered to have a disability if they answer yes to any of the following questions:</p> <ol style="list-style-type: none"> 1. Does this person have any of the following long-lasting conditions: <ol style="list-style-type: none"> a. Blindness, deafness, or a severe vision or hearing impairment? b. A condition that substantially limits one or more basic physical activities such as walking, climbing stairs, reaching, lifting, or carrying?

(continued)

Title: **National Transportation Availability Survey (cont.)**

Sponsoring Agency: Bureau of Transportation Statistics

2. Because of a physical, mental, or emotional condition lasting 6 months or more, does this person have any difficulty in doing any of the following activities:
 - a. Learning, remembering, or concentrating?
 - b. Dressing, bathing, or getting around inside the home?
 - c. Going outside the home alone to shop or visit a doctor's office?
 - d. Working at a job or business?

The Freedom to Travel report uses only the Census 2000 questions as the disability indicator. However, the public use data files and documentation include many different disability measures, allowing analysts to construct their own definition of disability using the multiple items in the survey.

Frequency: Once

Title:	National Vital Statistics System—Mortality and Natality
Sponsoring Agency:	National Center for Health Statistics/CDC
Website:	http://www.cdc.gov/nchs/deaths.htm http://www.cdc.gov/nchs/births.htm
Sample Methodology and Sample Size:	Information obtained from all birth and death certificates in the United States.
Definition of Disability:	None—information is retrieved from birth and death certificates.
Frequency:	Continuous

Title:	Pew Research Center for People and the Press Voter Survey (June 13, 2000)
Sponsoring Agency:	The Pew Research Center for the People and the Press
Website:	http://people-press.org/reports/display.php3?ReportID=35
Sample Methodology and Sample Size:	Nationwide sample of 2,174 adults, 18 years of age or older, during the period June 14-28, 2000.
Definition of Disability:	<p>The survey uses the Census definition of disability. Thus, an individual is considered to have a disability if they answer yes to any of the following questions:</p> <ol style="list-style-type: none"> 1. Does this person have any of the following long-lasting conditions: <ol style="list-style-type: none"> a. Blindness, deafness, or a severe vision or hearing impairment? b. A condition that substantially limits one or more basic physical activities such as walking, climbing stairs, reaching, lifting, or carrying? 2. Because of a physical, mental, or emotional condition lasting 6 months or more, does this person have any difficulty in doing any of the following activities: <ol style="list-style-type: none"> a. Learning, remembering, or concentrating? b. Dressing, bathing, or getting around inside the home? c. Going outside the home alone to shop or visit a doctor's office? d. Working at a job or business?
Frequency:	One time

Title:	Survey of Income and Program Participation
Sponsoring Agency:	U.S. Census Bureau
Website:	http://www.sipp.census.gov/sipp/
Dissemination of Results:	Public-use data file, several reports available on website.
Sample Methodology and Sample Size:	<p>Longitudinal survey conducted in waves, through telephone and in-person interviews.</p> <p>The recent panels (1996, 2001, and 2004) include 40,000 target households. Each household is interviewed 12 times over a four-year period.</p> <p>Each SIPP interview includes a core and topical module. The core questions, which address demographic, program participation, and employment information over the previous four-month period, are repeated in each wave of interviews. Topical modules cover a broad range of subjects that vary by interview wave within each panel. The modules also vary by panel and include questions on personal history, childcare, assets, program eligibility, child support, disability, school enrollment, taxes, and annual income.</p> <p>There is an oversampling of households in areas with high poverty rates.</p> <p>Each SIPP panel includes one question about the presence of a work limitation during the first (core) interview and more detailed questions about health, functional limitation status, and medical history in the topical modules.</p> <p>The Functional Limitations and Disability topical module, which contains the most comprehensive set of disability-related question and covers general health status, activities of daily living (ADLs), instrumental activities of daily living (IADLs) and, since the 1996 redesign, detailed questions on specific health conditions in addition to specific physical and mental conditions affecting the respondent: functional activity limitations, ADLs, IADLs, use of assistive equipment, mental functioning, and work disability.</p>

(continued)

Title: **Survey of Income and Program Participation (cont.)**

Definition of Disability: In most analyses, adults are considered to have a disability if they meet one of the following 6 criteria:

1. Work Limitations: reported a physical, mental, or other health condition that limits the kind or amount of work they can do.
2. IADLs: reported difficulties with activities such as going outside the home, keeping track of money or bills, doing light housework, and taking medication.
3. ADLs: reported difficulty with activities such as getting around inside the home, getting in and out of bed or a chair, taking a bath or shower, dressing, eating, or using the toilet.
4. Mental impairment: reported of learning or developmental disabilities and mental retardation, Alzheimer's disease or other serious problems with confusion or forgetfulness, and other mental or emotional conditions.
5. Physical: reported difficulty with lifting or carrying an object 10 pounds or heavier; pushing or pulling large objects; standing or sitting for one hour; stooping, crouching, or kneeling; reaching or grasping; walking three blocks or up a flight of stairs; or using a telephone.
6. Sensory: Reported difficulties with seeing, hearing, or having their speech understood.

Frequency: Since 1984, the Census Bureau has fielded 12 panels. The 2001 panel included nine interviews over four-month intervals of a nationally representative sample of the 2001 U.S. population in calendar years 2001 through 2003.

Source: Wittenburg and Nelson 2006

Title:	Survey of State Developmental Disability Directors
Sponsoring Agency:	University of Minnesota, Research and Training Center on Community Living National Residential Information Systems Project
Website:	http://rtc.umn.edu/publications/index.asp#risp
Dissemination of Results:	Annual reports available on website
Sample Methodology and Sample Size:	<p>Five-part survey of designated state agencies and key respondents to gather aggregated state statistics. Survey was mailed to each state's intellectual disabilities/developmental disabilities program director and the state's designated "key data informant."</p> <p>Survey requested information on the following:</p> <ol style="list-style-type: none"> 1. State residential services including state ICFs-MR. 2. Nonstate residential settings and residents with intellectual disabilities and related developmental disabilities including nonstate ICFs-MR. 3. Medicaid Home and Community-Based Services. 4. Number of persons with ID/DD on waiting lists for residential services. 5. Number of persons with ID/DD living in generic Medicaid nursing homes on June 30, 2005. <p>Telephone followup was used to promote initial response and to clarify and edit the statistics on returned questionnaires.</p>
Definition of Disability:	Consumers of Developmental Disability Services
Frequency:	Annual

Title:	National Survey of Recreation and the Environment
Sponsoring Agency:	National Center on Accessibility, U.S. Forest Service (1994-1995)
Website:	http://www.srs.fs.usda.gov/trends/Nsre/nsre2.html
Dissemination of Results:	NCA website, Forest Service website, data in various formats
Sample Methodology and Sample Size:	17,216 Americans over age 15—1,252 people said they had a disability (1994–1995 data). All were in-home surveys, except for 1999–2003, which was via telephone.
Definition of Disability:	Q345: During anytime in your life have you been diagnosed with a particular disability, impairment, or disabling illness?
Frequency:	1960, 1965, 1970, 1972, 1977, 1982–83, 1994–95, 1999–2003 . Analysis of results pertaining to disability found for only 1994–1995 data.

Appendix D: Limitations of Existing Data

This appendix elaborates on the major limitations of data related to people with disabilities, including the definition of disability, inclusion of individuals from cultural or linguistic minorities, and statistical limitations. In Chapter 4 and Appendix D, we elaborate on how the weaknesses limit the usefulness of certain data in each domain in measuring quality of life for people with disabilities.

Inadequate or inconsistent definition of disability: To illustrate, several surveys ask respondents if they have a “disability or medical condition that prevents or limits the amount or type of work you can do.” This item is often used to define “work limitation,” but such a question is likely to be answered negatively by some individuals with substantial impairments who a) are able to work despite their impairment or because they have an accommodation, or b) would not work even if they did not have an impairment. Conversely, the question could be answered positively by some individuals who do not have a substantial, long-term impairment, but are physically or mentally incapable of certain types of work. Further, answers are likely to be sensitive to characteristics of the economic or physical environment; individuals with some level of impairment who have been laid off or had difficulty finding work may answer the question positively.

As just noted, defining disability is complicated by the role of the environment. The disability paradigm posits that a “disability” is an interaction between an individual with an impairment and his or her environment, rather than a characteristic only of the individual. However, the available survey data generally do not allow researchers to construct definitions that recognize the role of the environment; few surveys ask about the availability of transportation, curb cuts, accessible buildings or other environmental features that facilitate integration. Instead, they focus on the characteristics of the individual that might put a person at risk for disability (e.g., need for assistance in performing activities of daily living) or imply that disability is an individual characteristic (“Do *you* have a disability...”), and are not explicit about what disability means.

In addition, the definition is often too broad to allow identification of important subgroups, such as people with psychiatric, vision, or hearing impairments. In surveys with a broad range of questions about disability status, the sample is often too small to consider subgroups except in a cursory way. This is an important issue for program evaluation because most programs target only a subset of the disability population.

Disability scholars have spent decades trying to define disability and the disablement process: the interrelated chain of events and personal or environmental circumstances that produce disability (Albrecht et al. 2001; Wunderlich et al. 2002). Dozens of formal definitions of disability exist, embedded within federal and state laws and regulations. Many appoint clinicians, primarily physicians, as arbiters, to determine whether individuals meet some established criterion for disability and thus deserve a benefit like income support, health insurance, or accessible parking license plates or placards.

Two definitions hold special relevance for Americans: the one used by the Social Security Administration (SSA), which focuses on work disability to determine eligibility for federal income support as well as health insurance coverage for millions of individuals; and the ADA, which makes discrimination illegal and requires accommodations by public and private entities for people who meet an ever-evolving definition of disability, including those who might not regard themselves to have disabilities, but whom others might consider to have disabilities. SSA relies on a definition that is essentially medical, while the ADA definition incorporates substantial social features (Iezzoni and O'Day 2006).

Inconsistent definitions used in the data collected on people with disabilities add to the confusion. As we have pointed out, all of these definitions have shortcomings; for example, the definition of disability used in the American Community Survey combines individuals with visual and hearing problems into one “sensory disability” category and individuals with mental health and intellectual disabilities into a “mental disability” category. The definition in the Current Population Survey defines disability as an impairment that prevents or limits work, which excludes many who are not work limited despite substantial impairments. None of them are inclusive enough for all situations and

most are too inclusive for some situations: for example, including all individuals with impairments when measuring the need for and use of personal assistance or technology.

We do not solve the “definition of disability conundrum” or become mired in attempting to show which definition is best. To do so would greatly circumscribe the scope of indicators that can be developed from existing data. Rather we recognize the difference in how each data source defines disability and note the particular data source used for each indicator. The exact definition of disability for each data source is described in Appendix C.

Inadequate inclusion of individuals from cultural or linguistic minorities: People from race-ethnic cultural minorities constitute a disproportionate share of the disability community and have a distinctive set of needs in addition to those experienced by other people with disabilities (NCD 1993). Recent survey data indicates that more than one-quarter of the disability population is non-white (see Exhibit D.1).

Exhibit D.1: Race-Ethnic Distribution of Working-Age People with Disabilities 21–64

	With Disability	Without Disability
White	73.6	75.7
Black/African American	15.5	11.1
Native American	1.5	0.7
Asian	2.4	5.1
Some other race	7.1	7.4

Source: ACS reported in StatsRRTC 2005

There is evidence that people with disabilities from culturally diverse backgrounds experience twice the discrimination in employment as their non-disabled cohorts. Disability and race compound discrimination (U.S. Department of Labor 1998).

Despite the need for data to understand these challenges, individuals from cultural and linguistic minorities are often not adequately represented in surveys. Often the sample

size of different minority groups is too small to create separate estimates for them. In many of the larger surveys, it is probably possible to measure this subpopulation. Although the tabulations are routinely produced by race and by disability status, they do not cross-tabulate race with disability status.

Limited ability to create a time series: In order to track the progress of people with disabilities in comparison to people without disabilities, we need consistent time series data. In other words, the survey must include the same question, the same disability indicators and the same sampling methodology across time. Unfortunately very few surveys allow this type of comparison. For example, the decennial census has changed the definition of disability several times. The N.O.D./Harris survey has a consistent definition of disability but changes most of the survey questions each year. When the ACS moved out of its development phase and into full implementation in 2005, the sample design was changed eliminating the ability to make multiyear comparisons of pre-2005 and post-2005 data. The CPS is a long established survey and has not changed the definition of disability since the work disability question was added to the survey in 1981. However, the definition has significant limitations, which have been discussed at length (Hale 2001, Silverstein et al. 2005).

Statistical limitations. Three types of measurement error are pervasive in the surveys commonly used to assess the status and progress of people with disabilities:

a. Sampling error: Any estimates derived from samples are subject to error because a different sample could result in different findings. The variation that exists among the estimates from the different possible samples is what makes the sampling error. The extent of the sampling error depends on the sampling method, the estimation method, the sample size and the variability of the estimated characteristic. The issue of sample size is recurring for several reasons.

First, some small surveys of important issues, such as the Pew survey of political participation, include a disability question but do not oversample the disability

population. As a result the sample size of people with disabilities is too small to create a reliable estimate.

Second, for many indicators, incremental and small movement in the value of the measure over time may suggest important changes. For example, a two percentage point change in the percent of people who socialized with friends at least twice a month among people with disabilities may be notable. However, the sampling error on the N.O.D./Harris survey, with a sample size of about 1,000 people with disabilities, is *roughly* plus or minus three percent. (Because N.O.D./Harris has chosen to keep the details of sampling and weighting procedures proprietary, it is not possible to make accurate estimates of the sampling errors of estimates.) Thus, although 79% of the sample population socializes with friends at least twice a month, the “true” value of the measure—the percent of the total population with disabilities that socializes at least twice a month is somewhere between 76 and 82%. The indicator has fluctuated between 79 and 82% since 1994. It is not possible to identify whether there has been no change in socializing behaviors or if the sample size is not adequate to capture that change.

Third, large sample sizes are needed to support detailed tabulations by age, sex, race, and other demographics, and most surveys do not sample enough individuals with disabilities to support these tabulations.

b. Coverage error: Most surveys exclude those who are living in institutions, including group homes, nursing homes, assisted living facilities, and prisons. She and Stapleton (2006) estimate that 6% of the population of people with disabilities (likely a larger percentage of those with mental illness or mental retardation) lives in institutions and are thus excluded from most surveys. The number of working-age males with disabilities who are living in prisons and jails appears to have grown rapidly over the last two decades, but has largely gone unnoticed. The surveys also exclude people who are homeless and many surveys exclude those without a telephone. It is very difficult to study the extent to which people with disabilities are able to live independently, in non-institutional settings, when we fail to quantify the number who are living in institutions or who are homeless. The ACS is beginning to survey the

population in institutions. The other large national surveys with disability indicators (BRFSS, NHANES, NHIS, and SIPP) and the smaller surveys (N.O.D./Harris) do not include people living in institutions.

c. Nonresponse error: The nature of a person's impairments or disabilities may result in different response rates among members of the population with disabilities. In order to reduce non-response, some surveys allow for proxy respondents. However, proxy respondents may provide different responses than self-reports.

Appendix E: Data on Individuals with Disabilities

This appendix reviews current data about people with disabilities, using the domains and dimensions identified by our focus groups as a guide. We review existing data by domain (employment, education, health and health care, financial status, community participation, leisure and recreation, political participation, transportation, housing, personal relationships, and technology.)

In each domain, we review what we know by the dimensions identified by the focus groups and assign a grade (A–F) to each dimension to indicate how comprehensive the current data measures the domain/dimension. This grading system is, by its nature, subjective. It is intended to give the reader a general sense of how well current data captures a particular area. The grading system is as follows:

- A—The domain/dimension is covered very well in a survey that is collected regularly, the definition of disability and the data element are consistent across years, and the results are published regularly
- B—There is data that could serve as a reasonable proxy for the element
- C—There is no time series available or the data is not readily available
- D—A reasonable proxy was collected on a small one-time only survey
- F—The domain/dimension is not covered in any current data collection instrument

Throughout the appendix we refer to the following age groups:

- Working age refers to people ages 21-64 unless otherwise noted.
- Adults refer to individuals over age 18.

Employment

(see Exhibits E.1–E.5)

The nation monitors important aspects of employment including wages, and employment and unemployment rates using the Current Population Survey (CPS). However, the definition of disability in the CPS—“do you have a health problem or disability which prevents you from working or which limits the kind or amount of work you can do”—is very controversial. This definition may overrepresent those with impairments who are not employed and miss those with impairments who are sufficiently integrated into the workforce that they do not report being work limited (Hale 2001, Silverstein et al. 2005).

Because of this and other controversies about measuring employment, we do not have an authoritative time series of a measure as basic as the employment rate for people with disabilities. What is clear from all the research is that there are a substantial number of people with disabilities who would like to work but are not working (Harris Interactive 2004, Stapleton and Burkhauser 2003).

Beyond the issue of whether a person has a job, the focus groups identified the following aspects of employment as important to their quality of life.

Exhibit E.1: Dimensions of Employment Reported in Current Surveys

Dimension	Indicator	Grade
Choice	If you want a job, you are able to get one. Choice in current employment. Job at proper skill level. Appropriate amount of stress	C
Spontaneity	Can participate with co-workers in unplanned social events	F
Aspirations	Set and pursue goals for employment, including promotion	F

(continued)

Exhibit E.1: Dimensions of Employment Reported in Current Surveys (cont.)

Dimension	Indicator	Grade
Empowerment	Job increases your self-esteem. Knowledge about employment provisions of ADA; can advocate for needed accommodations	F
Quality	Engaged in work that person finds meaningful	F
Finances	Wages, hours worked	C
Satisfaction	Satisfaction with your position, with pay and benefits, work hours. Satisfaction with job/leisure tradeoff	F
Inclusion/ integration	Feeling included in informal interactions or after work activities with co-workers; work in an integrated setting	F
Assistance and support	Receive help in finding and keeping employment; obtain assistance needed to solve problems or keep your job. Support readily available (without “red tape”)	D
Public attitudes	Supervisors and co-workers have appropriate expectations of you in performing job duties. Supervisors and co-workers’ “comfort level”	F
Accessibility	Worksite accessible. Job application process accessible; provided with all accommodations needed to do job, including flexible hours, assistive technology, etc.	F
Non- discrimination	Non-discrimination in hiring, firing, or promotion.	D
Safety/Risk	Job security. Able to work without fear of losing external benefits.	F

While current data allows us to monitor the employment and unemployment rate wages, it gives us little information about the aspects of employment that affect the quality of life for people with disabilities. For example, there are no measures of spontaneity, aspirations, quality, satisfaction, inclusion/integration, assistance and support, public attitudes, and safety/risk and only limited information on choice, empowerment, accessibility, and non-discrimination.

The March CPS has asked a nationally representative crosssection of the United States working-age population the same work limitation based-disability question since 1980. It is the only data set for which trends in the prevalence of a consistently defined population with disabilities, as well as the employment and economic well-being outcomes of this population, is available for such a long time period. Because of the controversy about the definition of disability, we do not report CPS statistics in this section.

Choice

There are no nationally representative sources that ask specifically about the ability to choose whether to work. However, several surveys including the ACS, CPS, SIPP, and NHIS measure the employment rate (calculated as the number working/total population) and the unemployment rate (calculated as the number not working/number looking for work). Each measure has limitations in measuring whether people who want to work are actually working. The employment rate includes, in the denominator, people who have no interest in working. The unemployment rate includes only people who are looking for a job and thus seems to capture the notion of choice a little better. However, it does not capture people who may wish to work but have left the labor market either because they are discouraged, they do not want to threaten their disability cash benefits (SSI or SSDI), or are not looking for work for other reasons. The N.O.D./Harris survey has addressed this issue by asking whether the respondent would "prefer" to work, rather than whether he or she is looking for work. The employment statistics we have are as follows:

- In 2005, the employment rate of working-age people with disabilities was 38 percent compared to 78 percent for working-age people without disabilities (ACS 2005 reported in RRTC Status reports).
- In 2005, 23 percent of working-age people with disabilities and 56 percent of working-age people without disabilities were working full-time/full-year (ACS 2005 reported in RRTC Status reports).
- In 2004, 63 percent of unemployed people with disabilities ages 18-64 would prefer to be working compared to 42 percent of people without disabilities (Harris Interactive 2004, based on 905 people with disabilities and 320 people without).

Pertaining to other aspects of choice, we know that:

- In 2000, employed people with disabilities were less likely than people without disabilities to report that their jobs required their full talents and abilities (Exhibit E.2, Harris Interactive 2000).

The other aspects of choice—ability to choose among jobs or have a job with appropriate amount of stress—are not captured in national surveys. There are several small, privately financed surveys cited by the National Institute of Occupational Safety and Health (Sauter et al. 1999) that ask workers about stress, but disability is viewed as an outcome from stress, not as a subpopulation.

Empowerment

In 2004, 63 percent of adults ages 18-64 with disabilities and 66 percent of adults without disabilities had "heard or read anything about a law called the Americans with Disabilities Act, or ADA." (Harris Interactive 2004—Note, this question does not specifically reference the employment provisions.) We know little about whether employment raises self-esteem or whether employees with disabilities can advocate for accommodations they need.

Employment—Finances

The median annual labor earnings (wages and salaries) of working age (ages 21–64) people who work full-time/full-year is \$30,000 for people with disabilities and \$36,000 for people without disabilities. (Exhibit E.3—2005 American Community Survey (ACS) data reported in StatsRRTC 2005)

Employment—Assistance and Support

Current available data does not provide a measure of the percentage of people with disabilities who receive employment assistance or the percentage who would like to receive assistance. The N.O.D./Harris survey asks about knowledge and use of Workforce Investment Act One-Stop Centers and finds that 42 percent of adults with disabilities have heard of one-stop centers and of those, 26 percent have used the

centers. For people without disabilities, 41 percent had heard of the centers and 22 percent of those had used the centers (Harris Interactive 2004).

Employment—Public Attitudes

There are no nationally representative surveys that address the issue of public attitudes from the perspective of the person with a disability. A 2002 survey of 501 employers asked personnel directors, human resources directors, and others in charge of hiring for their respective company, what was the greatest barrier to hiring people with disabilities (Dixon, Kruse, and Van Horn 2003):

- 32 percent said that the nature of their company's work is such that people with disabilities cannot effectively perform it.
- 18 percent said lack of skills and experience of the job seeker was a barrier to hiring.
- 15 percent cite their reluctance to hire workers with disabilities.
- 10 percent cite their discomfort or unfamiliarity regarding people with disabilities.
- 10 percent fear the cost of accommodating disability.

Other barriers include lack of information about job opportunities (7%), the need for special accommodation (7%), transportation issues (2%), and discrimination or prejudice (5%).

Non-Discrimination

The 2004 N.O.D./Harris Report found that 22 percent of working people age 18–64 with disabilities had encountered job discrimination because of their disability or health condition. Among those who had experienced discrimination, the most common type of discrimination was in the hiring process (Exhibit E.5, Harris Interactive 2004). The survey did not ask this question of people who were not employed so it is not a particularly good measure of discrimination in hiring.

Other Possible Data Sources

The ACS produces data on the unemployment rate, a measure of “choice”. This data currently exists for people with disabilities compared to people without disabilities, but is not included in any of the routinely-produced tables. In the fall of 2007, The Cornell StatsRRTC is planning to add the unemployment rate to the Annual Disability Status Reports.

The SIPP topical module on “education and training history” includes questions about the use of vocational training and a few details such as the length of time training was used and the payer. Although this does not directly address the assistance and support issues focus groups identified, it can be used as a measure of whether the respondent used an employment or vocational rehabilitation agency for training.

If the CPS had a “good” indicator of disability we would be able to develop an important proxy for quality of employment—hourly wage (overall and by education level), and choice—reason for unemployment (lose job, leave job), labor force participation rates, and alternative work arrangements.

Exhibit E.2: Perceptions of Talent Requirement of Their Own Job Among Employed Adults, 2000

	With Disabilities (n=228)	Without Disabilities (n=691)
Requires full talents and abilities	40	48
Some talents and abilities	35	40
Only a small amount of them	12	7
Practically none of them at all	8	3
Don't know	5	1

Source: Harris Interactive 2000

**Exhibit E.3: Employment Rate, Employment Type and Median Earnings
by Type of Disability, 2005**

	Employment Rate	Full-Time/ Full Year	Median Earnings for Full-Time/Full Year Employees
No Disability	78%	56%	\$36,000
Disability	38%	23%	\$30,000
Sensory Disability	47%	32%	\$32,000
Physical Disability	32%	19%	\$30,000
Mental Disability	29%	14%	\$26,000
Self-Care Disability	17%	9%	\$30,000
Go-Outside-Home Disability	17%	8%	\$29,300
Employment Disability	18%	8%	\$28,000

Source: 2005 ACS reported in StatsRRTC 2004

Exhibit E.4: Discrimination Based on Disability or Health Condition Among Employed Adults with a Disability 2004

	Percent
Any discrimination among employed people with disability (n=362)	22%
Type of discrimination among people who experienced discrimination (n=80)	
Refused a job because of your disability	31%
Refused a job interview because of your disability	27%
Denied a workplace accommodation	21%
Refused a promotion because of your disability	17%
Given less responsibility than your co-workers	14%
Paid less than other workers in similar jobs with similar skills	12%
Denied other work-related benefits	6%
Denied health insurance	4%
Other	25%

Source: Harris Interactive 2004

Education

(see Exhibits E.5-E.11)

Focus group members noted that access to quality education affected their ability to reach other goals such as employment and financial security. This relationship is borne out in the data. There is a stronger positive correlation between education and employment among people with disabilities than for the general population (Stodden 2002).

States provide strong ongoing data on early childhood education through high school in terms of the characteristics of special education students covered under the Individuals with Disabilities Education Act (IDEA) and the environment in which they are educated (percent of time in integrated classroom versus segregated classrooms) in response to federal reporting requirements. Information on post secondary school is less available and how well school prepares the students with disabilities for the future is not available.

The focus groups identified the following aspects of education as important to their quality of life.

Exhibit E.5: Dimensions of Education Reported in Current Surveys

Dimension	Indicator	Grade
Choice	Choice in where to go to school, not automatically directed to a special program; the opportunity to attend college	C
Spontaneity	Little advance preparation required to take a community education class	F
Aspirations	Set and pursue education goals	B
Empowerment	Campus disability office encourages independence; can advocate for needed accommodations	D
Quality	Education provided person the ability to get job/pursue dreams.	F
Finances	Able to obtain help to pay for education	C
Satisfaction	Satisfaction with the quality of your education	F
Inclusion/ integration	Educated in integrated classrooms	C
Assistance and support	Tutors/mentors available to you to help you solve problems or keep up with other students if needed	D
Public attitudes	Acceptance by student peers; high expectations of teachers	F
Accessibility	Specific needs accommodated such as slower pace of learning or sensory needs; Course materials accessible to you	D
Non-discrimination	Participation in a class or course denied	F

Because we are looking at adults rather than children, we focus on post secondary education and adult education.

Choice

- Students with disabilities are more likely to enroll in two-year institutions and less likely to enroll in 4-year institutions than students without disabilities (Exhibit E.9, NPSAS 2004).
- School age children with disabilities (age 6-21) are more likely to spend more than 80 percent of their day in a regular classroom in 2005 than in 1997 (IDEA data 2005).

- Students with disabilities in post secondary education are more likely to be in two-year rather than four year colleges and less likely to be pursuing a bachelors degree (rather than a certificate, associates degree, or no degree) compared to students without disabilities (Exhibit E.9, NSPAS 2004).

Aspirations

- In 2005, one-quarter of working age people (ages 21-64) with disabilities had less than a high school education compared with 12 percent of working age people without disabilities (2005 ACS reported in StatsRRTC 2005).
- The percentage of youth high students with disabilities entering college has more than doubled since 1987 (from 15% in 1987 to 33% in 2003), (NLTS as reported by Wagner et al. 2005).
- Among the 30 percent of youth in 2003 and the 46 percent in 1987 who had left high school without finishing, 22 percent in 2003 and 25 percent in 1987 had participated in a GED or other high school equivalency program (NLTS as reported by Wagner et al. 2005) or by taking an examination to obtain a General Educational Development (GED).

Finances

- A roughly equivalent percentage of students with disabilities receive aid for higher education than do their non-disabled counterparts. (Exhibit E. 10 NPSAS 2004 reported in Horn and Nevill 2006).

Support and Assistance

A one-time survey of disability support coordinators working in postsecondary institutions developed and administered by the National Center for the Study of Postsecondary Educational Supports at the University of Hawai'i at Manoa funded by the Department of Education, National Institute on Rehabilitation and Research (NIDRR) in 2000 found:

- While most postsecondary schools offered testing accommodations and personal counseling, few offered accessible transport on campus or real time captioning

(Exhibit E.11), (National Survey of Educational Support Provision to Students with Disabilities in Postsecondary Education 2000).

Other Potential Data Sources

The National Assessment of Adult Literacy includes a question about disability and measures three different types of literacy: 1) Prose literacy—knowledge and skills needed to understand and use information from texts that include editorials, news stories, poems, and fiction; 2) Document literacy—knowledge and skills required to locate and use information contained in materials that include job applications, payroll forms, transportation schedules, maps, tables, and graphs; and 3) Quantitative literacy—knowledge and skills required to apply arithmetic operations, either alone or sequentially, using numbers embedded in printed material. Although the sample size is adequate to support a comparison of literacy rates between people with and without disabilities, no such comparison has been produced.

The NSPAS includes a disability indicator and is a rich source of information about characteristics and financing post education. Although all of their standard tabulations that present data by demographics present the data by disability status, there is additional data that could be computed such as questions about the need and receipt of educational supports (Adaptive equipment and technology, alternative exam format, course substitution or waiver, readers or classroom note takers, registration assistance, sign language or oral interpreters, tutors to assist with ongoing homework). As far as we know, this data has not been tabulated.

There are multiple ways to calculate the dropout rate. IDEA requires that school systems keep track of the drop out rate for special education students but the calculation method is different from the method used by the National Center for Education Statistics to calculate the rate for non disabled students. Thus, there seems to be no good comparison.

Exhibit E.6: Educational Attainment of Working-Age People with Disabilities 2005

Education	With Disability	Without Disability
Less than High School graduation	25%	12%
High School graduation or Equivalent	35%	28%
Some College	28%	31%
Bachelor's Degree or more	13%	30%

Source: ACS 2005 reported in StatsRRTC 2005

Exhibit E.7: Percentage of Children Ages 6–21 Served in Different Educational Environments Under IDEA, Part B, During the 1997–98 School Year

Environment	Percent of all IDEA Students	
	1997/98	2005
Outside regular class		
< 21%	46%	54%
21-60%	29%	26%
> 60%	20%	17%
Public separate facility	2%	2%
Private separate facility	1%	1%
Public residential facility	<1%	<1%
Private residential facility	<1%	<1%
Home or hospital environment	<1%	<1%

Source: IDEA Source: Table 2-2. Students ages 6 through 21 served under IDEA, Part B, by educational environment and state: Fall 2005 https://www.ideadata.org/tables29th/ar_2-2.xls

Exhibit E.8: Changes in Postsecondary Education Participation Since High School of Youth with Disabilities 1987, 2003

Participated since leaving high school in:	1987	2003
Any Postsecondary education	15%	32%
2 year college	4%	21%
4-year college	1%	10%
Postsecondary vocational/technical/business school	12%	6%

Source: NLTS reported by Wagner et al. 2005.

Exhibit E.9: Characteristics of Post Secondary Education 2003/2004

	Without Disability	With Disability
Institutional Characteristics		
less than 2 year	3%	4%
2-year	42%	47%
4-year	47%	42%
more than one institution	8%	7%
Public	76%	76%
Private not for profit	15%	14%
Private for profit	8%	10%
Full-time/ full-year	42%	36%
Full-time/ part year	14%	15%
Part time/ full-year	23%	24%
Part time/part-year	22%	25%
Type of undergraduate program		
Certificate	7%	8%
Bachelor's degree	48%	42%
Non-degree	10%	11%
Associates degree	36%	39%

(continued)

Exhibit E.9: Characteristics of Post Secondary Education 2003/2004 (cont.)

	Without Disability	With Disability
Field of Study		
Arts and Humanities	13%	14%
Social and Behavioral Sciences	9%	9%
Life Sciences	5%	5%
Physical Sciences	<1%	<1%
Mathematics	<1%	<1%
Computer Information Sciences	6%	7%
English	5%	5%
Education	9%	8%
Business/management	20%	19%
Health	16%	16%
Vocational/technical	5%	6%
Other professional/technical	10%	19%

Source: NSPAS reported in Horn and Nevill 2006

Exhibit E.10: Financial Status and Aid for Post Secondary Education 2003/2004

	Without Disability	With Disability
Financial Status		
Dependent	51%	39%
Independent	49%	61%
Financial aid		
Received any aid	63%	63%
Received federal aid	46%	46%
Received any grants	51%	49%
Received any loans	35%	35%
Average total amount of aid	\$7,400	\$7,200
Average grant amount	\$4,100	\$3,700
Average loan amount	\$5,800	\$6,100

Source: NSPAS reported in Horn and Nevill 2006

Exhibit E.11: Provision of Selected Educational Supports among Post Secondary Institutions

	Not Offered	Sometimes Offered	Usually Offered
Summer Orientation Programs	57%	16%	27%
Priority Registration/Course Scheduling	24%	23%	54%
Class Relocation	16%	32%	53%
Testing Accommodations	4%	11%	84%
Disability-Specific Scholarships	59%	31%	10%
Disability-Specific Assessment/Evaluation	54%	25%	22%
Advocacy	9%	23%	68%
Supports for Study Abroad	63%	23%	14%
Learning Center Laboratory	27%	23%	51%
Special Learning Strategies	13%	42%	46%
Developmental/Remedial Instruction	28%	26%	47%
Personal Counseling	7%	24%	69%
Accessible Transport on Campus	57%	16%	27%
Interpreter/Transliterater	20%	23%	57%
Note Takers/Scribes/Readers	10%	23%	67%
Tutors	14%	30%	56%
Real-Time Captioning	71%	15%	15%
AT Evaluations	59%	25%	16%
Skills Training on Equipment/Software	29%	41%	30%
Equipment or Software Provision	35%	39%	26%
AT Supports across Campus	25%	41%	35%
Adaptive Furniture	23%	42%	36%
Document Conversion	34%	35%	31%
Communication Skills	26%	40%	35%
Study Skills	9%	32%	59%
Memory Skills	22%	41%	38%

(continued)

Exhibit E.11: Provision of Selected Educational Supports among Post Secondary Institutions (cont.)

	Not Offered	Sometimes Offered	Usually Offered
Meta-Cognitive Strategies	27%	42%	31%
Organizational and Time Management Skills	11%	37%	53%
Self-Advocacy Skills	15%	37%	48%
Career/Vocational Assessment and Counseling	11%	29%	61%
Work Experience of Work-Study Opportunities	15%	41%	44%
Internships/Externships	23%	39%	39%
Job Placement Services	21%	33%	46%
Facilitate Transfer of Supports to the Work Setting	54%	33%	13%

Source: National Survey of Educational Support Provision to Students with Disabilities in Postsecondary Education Settings: Technical Report, June 2000

Health and Health Care

(see Exhibits E.12-III.18)

There is a significant amount of data available on health and health care of people with disabilities, largely due to data sources such as the National Health Interview Survey, the Medical Expenditure Panel Survey, the Behavioral Risk Factor Surveillance System, the National Health and Nutrition Examination Survey, and the National Survey of Family Growth.

Despite the breadth of data available, many of the data sources used to monitor the health status of the general population do not include measures of disability including, for example, the National Vital Statistics Mortality and Natality System, communicable disease surveillance systems, the National Survey on Drug Use and Health, and the National Ambulatory Care survey. In fact, only one-third of the major population-based

surveillance items used for *Healthy People 2010* include standard measures of disability (*Healthy People 2010*).

The focus groups identified the following aspects of health and healthcare as important to their quality of life:

Exhibit E.12: Dimensions of Health and Health Care Reported in Current Surveys

Dimension	Indicator	Grade
Choice	Have choice among providers (doctors, psychiatrists, and specialists); where to receive care (home, hospital, or doctor's office); and insurance carriers. Have control over personal assistance and other supports (including control over whether to receive support services in an institution or in the community).	F
Spontaneity	Can participate in health and fitness activities without much advance planning.	C
Aspirations	Set and pursue goals for healthy living, including nutrition, exercise, etc.	C
Empowerment	Awareness of accessible medical resources. Able to take charge of your medical care. Medical treatment enables you to maintain health and independence.	F
Quality	Access to quality care irrespective of your insurance type; good relationship with healthcare provider. Health care needs addressed in a timely manner.	B
Finances	Able to afford needed care. Insurance and dental coverage, prescription drugs.	B
Satisfaction	Satisfaction with the quality of care you receive; care contributes to good health.	F
Inclusion/ integration	Inclusion in health promotion activities, such as exercise and nutrition classes.	C
Assistance and support	Specialized assistance available as needed, such as respite for families.	F
Public attitudes	Doctors and medical staff listen and respect your opinions. Asked about drug use, exercise and birth control. Doctors have knowledge about needs & resources. Public and doctors recognize the difference between illness and disability.	C

(continued)

Exhibit E.12: Dimensions of Health and Health Care Reported in Current Surveys (cont.)

Dimension	Indicator	Grade
Accessibility	Doctor's office or hospital accessible. Equipment (exam tables, X-ray machines); information about insurance health records or providers in alternate formats; medical staff assists as needed.	F
Non-discrimination	Health care or insurance, treatments forced or denied because of disability.	F
Safety/Risk	Back up system and benefits for personal assistance. Medical professionals asking people with disabilities the same questions about drug use, sexual activity, fitness as they ask others.	F
Other	Have access to reliable medical care (PCP), tailored to your needs; have access to equipment that is not medically necessary. Access to health care separate from income support.	F

Although none of the current data sources directly measure choice, spontaneity, aspirations, empowerment, quality, assistance and support, accessibility or non-discrimination, they do provide data on quality, finance, satisfaction, public attitudes and, to a lesser extent, inclusion/integration and safety/risk. Because of the quantity of data available on health and health care, we present only a fraction of data available on insurance, expenditures, and access. For example:

Finances

- The percentage of adults 18–64 with disabilities who have some type of health insurance has remained relatively constant at 84–86 percent since 1998 compared to 83–84 percent of for people without disabilities. (NHIS data reported in *Healthy People 2010*).
- People with disabilities are much more likely than people without disabilities to rely on public health insurance (Exhibit E.13, 2003 MEPS data as reported in Iezzoni and O’Day 2006).

- Median health care costs and out-of-pocket expenditures are much higher for people with an impairment than for people without an impairment. The costs differ dramatically by type of impairment (Exhibit E.14, 2003 MEPS data as reported in Iezzoni and O'Day 2006).
- In 2004, 28 percent of people with disabilities reported putting off or postponing seeking care that they felt they needed because of cost compared to 15 percent of people without disabilities. In 2000, 28 percent of people with disabilities and 12 percent of people without disabilities reported putting off or postponing care (Harris Interactive 2000 and 2004).
- In 2004, 18 percent of people with a disability over 18 reported that there was a time in the past 12 months when they needed medical care but did not get it compared with 7 percent of people without a disability (Harris Interactive 2004).

Quality

- Adults 18-64 with disabilities are slightly less likely to lack a usual source of care than those without disabilities (Exhibit III.15, 2003 MEPS data as reported in Iezzoni and O'Day 2006).

Aspirations—Participate in physical activity:

- In 2005, over half (55%) of adults with disabilities participated in no leisure time physical activity compared to 37 percent of people without disabilities. This disparity has held relatively constant between 1997 and 2005 (NHIS data reported in *Healthy People 2010*).

Public Attitudes

- In 2004, 57 percent of adult patients with disabilities reported that doctors or other health providers always show respect for what they have to say compared to 63 percent of patients without disabilities (Exhibit E.16, MEPS data reported in *Healthy People 2010*).

Other

- Compared with adults without disabilities, adults with physical and sensory disabilities report much higher rates of feeling frequently depressed or anxious, having serious difficulties coping with day-to-day stresses, and experiencing phobias or strong fears (Exhibit E.17, National Health Interview Survey-Disability, 1994/5 reported in Iezzoni and O'Day 2006).
- People with disabilities are more likely to have feelings that prevent them from participating in some activities than people without disabilities. Latinos with disabilities are the most likely to have feelings which prevent participation (Exhibit E.18, National Health Interview Survey reported in *Healthy People 2010*).

Other Possible Data Sources

The MEPS includes questions about access and quality for example:

- Does the doctor spend enough time with you? Listen to you?
- Are you able to get an appointment as soon as you wanted?
- General rating of health care received 1-10

However, although MEPS produces standard tables on these factors, the tables do not include aggregation by disability status. They include only age, sex, race, health insurance status, poverty status, metropolitan area/nonmetropolitan area, census region, and perceived health status.

In 1994, the NHIS asked a series of questions about the quality of the medical care interaction. These questions have not been repeated.

- During your last checkup were you asked about:
 - Your diet and eating habits?
 - The amount of physical activity or exercise you get?
 - Whether you smoke cigarettes or use forms of tobacco?

- How much and how often you drink alcohol?
- Whether you use marijuana, cocaine, or other drugs?
- If less than 65: Sexually transmitted diseases?
- If less than 50: The use of contraceptives?

Several important data sets do not include disability indicators including the National Vital Statistics System Mortality and Natality (NVSS-M, NVSS-V), the Prenatal care and birth outcomes (CDC)—includes age and race of mother but not disability status of mother), and the National Survey on Drug Use and Health (NSDU, SAMHSA)

One standard measure of access to ambulatory care is hospitalizations for ambulatory care sensitive conditions. *Healthy People 2010* produces this data using the Health Care Cost and Utilization Project (HCUP)—National Hospital Discharge surveys and database. Neither of these sources include a disability indicator.

Exhibit E.13: Health Insurance Coverage for Working-Age Persons, 2001

Impairment	Any Private Insurance	Public Insurance Only*	Uninsured*
No impairment	79%	6%	15%
Vision impairments			
Some	69%	14%	17%
Blind or major	52%	27%	21%
Hearing impairments			
Some	72%	14%	14%
Deaf or major	76%	7%	17%
Lower extremity mobility difficulty			
Minor	75%	14%	11%
Moderate	49%	39%	12%
Major	41%	47%	11%
Upper extremity mobility difficulty			
Some	53%	28%	19%
Major	49%	40%	12%
Difficulties using hands			
Some	47%	35%	18%
Major	40%	48%	13%
Any impairment	67%	17%	15%
Any major impairment	53%	30%	17%

Data source: 2001 Medical Expenditure Panel Survey reported in Iezzoni and O'Day (2006), p. 38.

*Public insurance = Medicare, Medicaid, or Medicare and Medicaid. Uninsured = lacking insurance for entire prior year.

Exhibit E.14: Median Total Health Care Expenditures and Out-of-Pocket Payments in 2001

Impairment	Age 18-64		Age 65+	
	Total (\$)	Self (\$)	Total (\$)	Self (\$)
No impairment	\$408	\$92	\$1,885	\$514
Vision impairments				
Some	\$1,418	\$330	\$3,594	\$987
Blind or major	\$1,477	\$308	\$4,811	\$971
Hearing impairments				
Some	\$1,638	\$357	\$4,234	\$812
Deaf or major	\$1,060	\$400	\$4,179	\$808
Lower extremity mobility difficulty				
Minor	\$2,993	\$532	\$3,760	\$905
Moderate	\$4,207	\$704	\$4,825	\$877
Major	\$7,389	\$815	\$6,528	\$1,226
Upper extremity mobility difficulty				
Some	\$4,278	\$723	\$4,536	\$936
Major	\$6,758	\$733	\$7,155	\$1,205
Difficulties using hands				
Some	\$4,369	\$758	\$5,454	\$1,167
Major	\$6,915	\$560	\$5,489	\$1,085
Any impairment	\$2,164	\$387	\$4,228	\$904
Any major impairment	\$3,826	\$510	\$5,317	\$1,098

Data source: 2001 Medical Expenditure Panel Survey as reported in Iezzoni and O'Day (2006), page 58.

Exhibit E.15: Persons Without a Usual Source of Care, 2001

Impairment	18–44 Years	45–64 Years	65+ Years
No impairments	22%	16%	8%
Vision impairments	26%	14%	8%
Hearing impairments	21%	13%	5%
Lower extremity mobility difficulty	20%	9%	4%
Upper extremity mobility difficulty	17%	10%	4%
Difficulties using hands	16%	9%	4%
Any impairment	23%	12%	5%
Any major impairment	21%	11%	5%

Data Source: 2001 Medical Expenditure Panel Survey reported in Iezzoni and O'Day (2006), page 54.

Exhibit E.16: Patient-Physician Communication Among Adults**Age 18 and Over, 2004**

Measure	With Disability	Without Disability
Patients reporting that doctors or other health providers always listen carefully to them	55%	59%
Patients reporting that doctors or other health providers always explain things so they can understand	54%	61%
Patients reporting that doctors or other health providers always show respect for what they have to say	57%	63%
Patients reporting that doctors or other health providers always spend enough time with them	46%	50%

Source: Medical Expenditure Panel Survey (MEPS) reported in *Healthy People 2010*.

Exhibit E.17: Reports of Mental Health Problems: Percent Reporting Depression, Stress or Strong Fears, by Impairment and Impairment Type, Adults Ages 18–64, 1994

	Depression	Stress	Strong Fears
Impairment			
No disability	3%	1%	3%
Blind or very low vision	25%	14%	13%
Deaf or hard of hearing	17%	9%	11%
Lower extremity mobility difficulty			
Some	24%	13%	14%
Major	34%	20%	17%
Upper extremity mobility difficulty			
Some	26%	15%	16%
Major	36%	22%	19%
Difficulty using hands			
Some	25%	14%	16%
Major	34%	21%	22%

Data source: 1994-1995 National Health Interview Survey Disability reported in Iezzoni and O'Day 2006.

Exhibit E.18: Percent of People With and Without Disabilities Who Report Feelings that Prevent Activity, by Race and Other Socioeconomic Status, Age 18 and Older, 1994

	With Disabilities	Without Disabilities
All	28%	7%
Race and ethnicity		
American Indian or Alaska Native	22%	15%
Asian or Pacific Islander	30%	7%
Asian	DSU	6%
Native Hawaiian and other Pacific Islander	DSU	14%
Black or African American	31%	8%
White	28%	7%
Hispanic or Latino	40%	9%
Not Hispanic or Latino	27%	7%
Black or African American	31%	8%
White	27%	6%
Gender		
Female	30%	8%
Male	26%	6%
Family income level		
Poor	38%	13%
Near poor	30%	10%
Middle/high income	21%	6%
Education level (aged 25 years and older)		
Less than high school	34%	10%
High school graduate	29%	7%
At least some college	25%	5%
Geographical location		
Urban	29%	7%
Rural	26%	6%

DSU = Data are statistically unreliable.

Note: Age adjusted to the year 2000 standard population.

Data: NHIS 1997 reported in *Healthy People 2010*.

Financial Status and Security

(see Exhibits E.19-E.21)

The relationship between financial status and happiness is, as one researcher put it, “puzzling” (Easterlin 2001). At any point in time people with more income are, on average, happier than those with less. However, over the life cycle, the average happiness of a cohort remains the same despite its income growth. Clearly money isn’t everything, but it is an important measure of well-being, and 21 percent of people with disabilities were below the poverty level versus 11.3 percent of those without a disability (ACS reported in StatsRRTC 2005).

The focus group identified other important aspects of financial status:

Exhibit E.19: Dimensions of Financial Status and Security Reported in Current Surveys

Dimension	Indicator	Grade
Choice	Choose where and when to spend money; choose to work to capacity without loss of needed benefits	C
Spontaneity	Financial resources to make spontaneous plans and decisions	F
Aspirations	Set and pursue financial goals; parents can save for their children’s future. Income/assets adequate to pursue long term goals	C
Empowerment	Control own finances or choices in who controls; understanding of work incentives if applicable; understanding of principles of asset accumulation	F
Quality	Financial resources enable high quality of life	F
Finances	Income (\$\$)	B
Satisfaction	Satisfaction with financial resources	F
Inclusion/ Integration	Included in courses on asset accumulation and retirement planning	F
Assistance and Support	Assistance in managing finances, navigating SSA and other work incentives	F
Accessibility	Banks including ATMs are accessible; information on financial management and investments is accessible.	F
Non-discrimination	Discrimination in lending	F

Financial Security

The N.O.D./Harris Survey asked whether a person holds certain assets: savings account with a bank, savings account with a credit union, Individual Development Account, corporate or municipal stocks or bonds, or government savings bonds. The survey found that people with disabilities are less likely to use financial institutions than people without disabilities (Exhibit E.20: Harris Interactive 2004). For example

- 69 percent of adults with disabilities have a checking account and 46 percent have a savings account compared to 76 percent with a checking account and 65 percent with a savings account among adults without disabilities (Harris Interactive 2004).
- 26 percent of people with disabilities have a loan with a bank compared to 36 percent of people without disabilities (Harris Interactive 2004)

Spontaneity: While no survey asks about the amount of savings, the N.O.D./Harris Survey asked about liquid assets that could be used in an emergency situation. They ask, "[i]f you had to support yourself for three months with no earned income or gifts from others, would you have enough financial assets to get by? By 'financial assets,' I mean savings and checking accounts, stocks, bonds, or trust funds." This is a very interesting way of getting at financial security and perhaps the ability to change jobs and make other spontaneous decisions. The survey found the following:

- 40 percent of people with disabilities have enough assets to cover expenses for three months compared to 62 percent of people without disabilities (Harris Interactive 2004).

Financial Security (Amount of Income)

- In 2005, the median household income of working age people (ages 21–64) with disabilities was \$35,000 compared to \$61,500 for working age people without disabilities (ACS 2005 reported in StatsRRTC 2005).

- In 2003, over one-quarter (26%) of people with disabilities had household incomes of less than \$15,000 compared to 9 percent of people without disabilities (Exhibit E.21, Harris Interactive 2004).

Potential Sources of Data

The ACS collects detailed information about family and household income. The pre-produced tabulations include median income, income distribution, poverty status, ratio of income to poverty by race, age, education and other variables. However, even though it is possible, the tabulations do not include these variables by disability status or by disability status crossed with any other demographic characteristic.

Focus group members thought an important indicator is whether people with disabilities could choose to work to capacity without losing needed cash and health benefits. The 2004 N.O.D./Harris Survey asked unemployed persons with disabilities who said that they would like to work why they were not working. They had to choose one main reason among four choices: unable to work due to a health problem or disability; cannot find a job that accommodates your disability; might lose your income assistance or health benefits if you get a job; or, some other reason. Only 2 percent responded "I might lose my income assistance or health benefits." This is likely an underestimate of whether people with disabilities can work without fear of losing their benefits because it may be one of several reasons they are not working.

Exhibit E.20: Percent of Adults With and Without Disabilities Who have Certain Types of Financial Accounts, 2004

	With Disabilities	Without Disabilities
Savings account with a bank	46%	65%
Savings account with a credit union	28%	37%
Individual Development Account	6%	13%
Corporate or municipal stocks or bonds	21%	34%
Government savings bonds	15%	21%
Checking account with a bank	69%	76%
Checking account with a credit union	22%	24%

	With Disabilities	Without Disabilities
Loan with a bank	26%	36%
Loan with a credit union or other financial institution	19%	23%

Source: Harris Interactive 2004

Exhibit E.21: 2003 Household Income

	With Disabilities			Without Disabilities		
	1998	2000	2004	1998	2000	2004
\$15,000 or less	34%	29%	26%	13%	10%	9%
\$15,001 to \$25,000	17%	17%	20%	13%	11%	12%
\$25,001 to \$35,000	12%	14%	12%	17%	10%	13%
\$35,001 to \$50,000	12%	11%	12%	20%	14%	13%
\$50,001 to \$75,000*	12%	11%	12%	27%	18%	20%
\$75,001 to \$100,000		3%	4%		10%	11%
\$100,001 or over		2%	4%		12%	10%
Don't know or refused		8%	11%		5%	11%

* In 1998 this category includes all incomes over \$50,000

Source: Harris Interactive 1998, 2000, 2004

Community Participation

(see Exhibits E.22-E.25)

There is limited data available on community participation among people with disabilities. The ongoing surveys which include this type of data are N.O.D./Harris survey and the NHIS. Most of the aspects of community participation identified as important by the focus groups are not covered in any existing surveys.

Exhibit E.22: Dimensions of Community Participation Reported in Current Surveys

Dimension	Indicator	Grade
Choice	Choices among a variety of community activities, including religious activities	C
Spontaneity	Amount of planning required to participate in a community activity. Change in this over time	F
Empowerment	Able to ask strangers for assistance when needed and refuse it when unneeded; understanding of own disability and can explain it to others	F
Finances	Able to afford to pay for activities in which you want to participate	F
Satisfaction	Satisfaction with your level of participation	F
Inclusion/ integration	Able to afford to pay for activities in which you want to participate	F
Assistance and support	Satisfaction with your level of participation	F
Public attitudes	Treated with dignity and respect (People do not address your companion rather than you)	F
Accessibility	Public facilities meet physical access standards. Usable—bathrooms, parking. Access laws enforced. Community agencies provide interpreters and alternative formats when requested	F
Non-discrimination	Denial of access	F
Safety/Risk	Crime. Feeling of safety (Feel safe moving around the community at night/during the day). Curb cut problems, being able to access all areas safely	F

Overall Community Participation

- One in 5 adults with a disability leave their house two or fewer times per week compared with one in 25 people without a disability. (Exhibit E.23, Bureau of Transportation Statistics 2003a).
- Adults with disabilities were less likely to participate in community activities such as worshipping at least once a month and going to a restaurant at least once a week. These two measures have been collected five times since 1986 and the differences between people with and without disabilities were found in every data year, although the magnitude of the differences varied from year to year (Exhibit E.24, Harris Interactive 2004).
- In 2001, with funding from the Office of Disability and Health, Centers for Disease Control and Prevention, the NHIS added the following supplementary questions:
“In the past two weeks did you . . .
 - go to church, temple, or another place of worship for services or other activities?
 - go to a show or movie, sports event, club meeting, class or other group event?
 - go out to eat at a restaurant?”

Based on these questions, *Healthy People 2010* reports that 61 percent of adults with disabilities participate in these social activities. The rate varies by race/ethnicity, gender, education level, and family income level. For example, 70 percent of people with disabilities with at least some college reported participating in these activities compared to 45 percent of those with less than a high school education (Exhibit E.25, NHIS reported in *Healthy People 2010*).

Other Potential Sources of Data

The NHIS estimates are the strongest statistics currently available on community participation among people with disabilities. Because the NHIS is based upon a large sample with a sample design, it is possible to produce the estimates by a variety of

demographic characteristics. However, questions about community participation were included on the 2001 NHIS but have not been repeated so no time series exists. The questions might be repeated in the NHIS if funding were available.

The NHIS has a series of ongoing questions in the adult questionnaire each year which are sometimes used to measure community involvement. The survey asks “By yourself and without using any special equipment, how difficult is it for you to... 1) Go out to things like shopping, movies, or sporting events? 2) Participate in social activities such as visiting friends, attending clubs and meetings, going to parties...? 3) Do things to relax at home or for leisure (reading, watching TV, sewing, listening to music...)?” The possible answers are “not at all difficult, only a little difficult, somewhat difficult, very difficult, can’t do at all, and do not do this activity. In fact, estimates based on these questions in the 1997 NHIS were used as the original baseline data for *Healthy People 2010* Objective 6-4, “Increase the proportion of adults with disabilities who participate in social activities.” However, the manner in which the answers to the several questions were combined into a single indicator is not described. (The baseline estimates can be found at <http://www.healthypeople.gov/Document/HTML/Volume1/06Disability.htm>.) CDC determined that the 2001 question was a better option for *Healthy People 2010*.

Each year, the N.O.D./Harris asks questions about community participation. The only measures that have remained constant over time are worshipping and going to a restaurant but other measures were included in some of the surveys: shopping at a supermarket or food store, shopping at a mall or shopping center, going to movies or theater, attending music performances, and attending sporting events.

The CPS asks about volunteering and characteristics of the volunteer experience but it does not include a good disability measure.

The American Time Use Survey queries how the respondent spent their time the previous day, where they were, and whom they were with. Among other things, it captures volunteering, participating in religious activities, socializing, exercising and relaxing.

However, the ATUS sample is drawn from CPS respondents and includes only the CPS disability measure.

In terms of feeling safe when participating in community activities, no national surveys ask about the feeling of safety, but two surveys ask about being a victim of crime. The National Crime Victimization Survey (NCVS) has just added a disability indicator to its survey and the data should be available in 2009. The BRFSS has optional modules on sexual violence and intimate partner violence but in 2006, only 14 states used the sexual violence module and 8 states used the intimate partner violence module.

Exhibit E.23: Percent of People With and Without Disabilities by Number of Days per Week They Leave Home, 2002

Frequency of Leaving the House	With Disabilities	Without Disabilities
Never	4%	1%
1-2	17%	4%
3-4	18%	8%
5-7	62%	88%

Source: 2002 National Transportation Availability and Use Survey reported in U.S. Department of Transportation, Bureau of Transportation Statistics (2003a). Table 1.

Exhibit E.24: Percent of Adults Who Participated in Selected Community Activities by Disability Status and Data Year: United States, 1986-2004

Measure of Community Participation and Disability	1986	1994	1998	2000	2004
Worship at least once a month					
No disability	66	58	57	65	57
Any disability	55	49	54	47	49
Go to restaurant at least once a week					
No disability	58	55	60	59	73
Any disability	34	34	33	40	57

Source: Harris Interactive

Exhibit E.25: Social Participation Among Adults with Disabilities (Age Adjusted, Aged 18 and Over), 2001

Characteristic	Percent with Social Participation
All	61
Race and ethnicity	
American Indian or Alaska Native only	66
Asian only	54
Black or African American only	59
White only	61
2 or more races	57
Hispanic or Latino	56
Not Hispanic or Latino	61
Gender	
Female	64
Male	57
Education level (persons aged 25 years and older)	
Less than high school	45
High school graduate	57
At least some college	70
Family income level	
Poor	47
Near poor	54
Middle/high income	69
Geographic location	
Urban (metropolitan statistical area)	60
Rural (nonmetropolitan statistical area)	61

Source: NHIS reported in *Healthy People 2010*

Leisure and Recreation

(see Exhibits E26)

There is limited data available on leisure and recreation among people with disabilities. The NHIS queries about leisure-time physical activity, but no other large national survey with a disability indicator asks about leisure-time activities. There is overlap between the categories of community participation and leisure and recreation and the category of community participation. The focus groups identified the former as interacting with other members of the community where the latter could be a solitary activity.

Exhibit E.26: Dimensions of Leisure and Recreation Reported in Current Surveys

Dimension	Indicator	Grade
Choice	Choices in how you spend your leisure time; in solitude, with others, etc.	F
Empowerment	Can advocate for accommodations in leisure activities	F
Finances	Able to pay for leisure time activities—travel, hobbies, etc.	F
Satisfaction	Satisfaction with leisure activities	F
Assistance and support	Specialized leisure opportunities available that promote peer support and socialization	F
Public attitudes	Leisure activities are physically and programmatically accessible (public and private)	F
Accessibility	Denial of access	F
Non-discrimination	Leisure activities are physically and programmatically accessible (public and private)	F
Other	Have enough time for leisure	F

In 1995, the US Forest Service conducted the National Survey on Recreation and the Environment (NSRE) which provides information on the status of people with disabilities in the areas of recreation and leisure. The NSRE has a sample of 17,216 people over age 15 and over 1,200 identified themselves as having a disability (McCormick 2000). This is a rich source of data on leisure and recreation activities among people with disabilities.

McCormick (2000) analyzed the survey; however, because of the age of the survey, it is difficult to access specific survey results. As a result, we can report only broad findings.

Choice

Based on the NSRE, in 1995:

- People with disabilities reported not participating in recreational activities because of a “lack of available partners” approximately as often as people without disabilities reported that issue.
- Patterns of participation in outdoor recreation were similar across most activities for people with and without disabilities. Activities with the highest rates of participation among people without disabilities also tended to show the highest rates of participation among people with disabilities.
- Overall, people with disabilities participated at rates equal to, or somewhat lower than people without disabilities.
- In most outdoor recreation activities, people with disabilities in middle age groups reported less frequent participation than people without disabilities; however in the youngest and oldest age groups, people with disabilities participated at rates equal to, or greater than, people without disabilities.
- In nature study activities, people with disabilities participated at rates higher than those of people without disabilities.
- Although most people with disabilities reported experiencing few barriers to outdoor recreation, barriers of health conditions and physical limitations were experienced by the majority of people with disabilities.

Accessibility

The Open Doors Organization survey found that 84 percent of people who had used air travel found “obstacles” involving airline employees, and 82 percent said there were obstacles at the airports. This survey also found that people with disabilities who

stayed overnight at a hotel, motel, etc. had physical (48%) or communication (15%) barriers (ODO, 2005).

Other

The 2000 Harris Survey found that people with disabilities did not go shopping (23% versus 41%), to the theater (22% versus 48%), to live music events (9% versus 16%), sporting events (15% versus 35%), or other events related to hobbies (21% versus 36%) as often as people without disabilities (Harris Interactive 2000).

Political Participation

(see Exhibits E.27-E30)

The major sources of data about political participation among people with disabilities is from the N.O.D./Harris survey, a 2000 survey by the Pew Research Center for the People and the Press, and a small survey done by Rutgers University. Interestingly, the N.O.D./Harris and the Pew Research results on voting for 2000 seem to differ sufficiently to draw different conclusions about whether people with disabilities had the same or lower voter turnout than people without disabilities.

As our focus groups identified, political participation extends beyond voting. There is not information about participation beyond voting.

Exhibit E.27: Dimensions of Leisure and Recreation Reported in Current Surveys

Dimension	Indicator	Grade
Choice	Choice among candidates that represent disability interests	C
Spontaneity	Can attend political events (fundraisers) held in private homes	F
Aspirations	Able to run for office or achieve other political appointment	F
Empowerment	Participation in a disability or other advocacy organization. Feel that have a voice in the political process	F
Finances	Can contribute to political candidates if desired; can participate in fundraisers, etc.	F
Satisfaction	Satisfied with voice in the political process	F
Inclusion/ Integration	Feel included in political functions, people with disabilities hold political offices	F
Assistance and support	Receive assistance with voter registration or understanding the political process if needed	C
Public attitudes	How people in public office discuss disability issues	F
Accessibility	Voting machines accessible to you. Process accessible: obtaining ID cards, getting to the polling place	C
Non-discrimination	The opportunity to vote	C

Choice

- Although people with disabilities have historically been less likely than people without disabilities to vote in Presidential elections, this gap closed considerably in the 2004 election season. People with disabilities were almost as likely as those without disabilities to vote in the 2004 elections, with turnout for these populations estimated

at 52 percent and 56 percent respectively – a gap of only four percentage points compared to an 11 point gap in 1992 and a 17 point gap in 1996 (Exhibit E.28: Harris Interactive 2004).

- Although people with disabilities have been significantly more likely to vote for the Democratic Presidential candidate in the 1992, 1996, and 2000 Presidential elections, in 2004 they were more likely to vote for the Republican candidate, President George W. Bush—with 53 percent supporting Bush as compared to 46 percent voting for Kerry (Exhibit E.29: Harris Interactive 1998, 2000 and 2004).

Accessibility

In 2001 the Government Accountability Office (GAO) visited a nationally representative sample of 497 polling places in the contiguous United States on election day (Nov. 7, 2000) and found:

- 33 percent of polling places lacked access to parking for people with physical disabilities, 57 percent had barriers between parking and the building entrance, and the route from inside of the building to the voting room had limited accessibility in 14 percent of the polling places (Exhibit E.30: GAO 2001).

Following the 2000 elections, researchers at Rutgers University conducted a national random-household telephone survey of 432 American citizens of voting age with disabilities and 570 without disabilities. They found:

- People with disabilities were almost twice as likely as other citizens to vote by absentee ballot. Among those who voted, 20 percent used an absentee ballot, compared to 11 percent of people without disabilities (Shur et al. n.d.)
- Citizens with disabilities are more likely than those without disabilities to have encountered, or expect, difficulties in voting at a polling place (Exhibit E.31, Shur et al. n.d.)

The Pew Research Center for the People and the Press conducted a telephone survey among a nationwide sample of 2,174 adults in June 2000. It is one of the few privately

funded public opinion polls that asked questions to identify people with disabilities. Based on the 21 percent (460 respondents) who identified themselves as having a sensory, physical, or mental or emotional condition, “Voter Turnout May Slip Again,” released July 2000 by The Pew Research Center for the People and the Press. reported the following:

- For the most part, voter registration and intentions to vote are as high among people with disabilities as in the rest of the population. There is one important exception: Those who identify themselves as having physical, mental or emotional conditions that increase the difficulty of learning, remembering or concentrating report lower rates of registration and regular voting than the general public.
- While disabled people vote at relatively high rates, they more often cite getting to the polls as a barrier to voting compared to the general public. Among those who do not always vote, 44 percent of people with conditions that impair physical activity mention this as a reason for not voting. By contrast, only 26 percent of the public cites this as a reason for not voting.

Potential Sources

The November Current Population Survey collects data about voting and registration. However, the disability indicator is controversial, as mentioned above.

Exhibit E.28: Voter Turnout 1992–1996 by Disability Status

Voter Turnout	With Disability	Without Disability
1992*	45%	56%
1996*	33%	50%
2000	41%	52%
2004	52%	56%

Source: Harris Interactive 1994, 1998, 2000 and 2004 as reported in the 2004 report.
 *The 1994 N.O.D./Harris survey asked about participation in the 1992 elections. The 1998 survey asked about the 1996 election.

**Exhibit E.29: Voter Preferences in Presidential Election Years
by Disability Status, 1992–2004**

	Without Disabilities	With Disabilities
2004		
Bush (George W.)	53%	51%
Kerry	46%	48%
Nader	1%	1%
Other	0%	0%
2000		
Bush (George W.)	38%	48%
Gore	56%	46%
Nader	4%	5%
Other	2%	1%
1996		
Clinton	69%	50%
Dole	23%	40%
Perot	5%	10%
Other	3%	1%
1992		
Clinton	52%	43%
Bush (George H.W.)	29%	38%
Perot	17%	19%
Other	2%	0%

Source: N.O.D./Harris Poll, selected Presidential election years.

**Exhibit E.30: Physical Access to Polling Places: Selected Potential Impediments
by Location Area**

Parking area	33%
No parking designated for people with disabilities	32%
No parking for any voters	1%
Route from parking area to building entrance	57%
Unpaved or poor surface	23%
Ramps with slopes greater than 1:12	21%
Sidewalk slope steeper than 1:12	20%
Unramped or uncut curb(s)	8%
No sidewalk or pathway for part of the way	8%
Ramps that measure more than 6 inches from the ground to the highest point and lack two handrails	6%
Steps have no handrails	5%
Entrance to the building	59%
Door thresholds greater than ½-inch in height	37%
Closed doors that would be difficult for a person in a wheelchair to open	26%
Single-door openings less than 32 inches wide	10%
Double-door openings less than 32 inches wide	5%
Route from inside of the building to the voting room	14%
Single-door openings less than 32 inches wide	5%
Closed doors that would be difficult for a person in a wheelchair to open	3%

Notes: Potential impediments listed are those that occurred with the greatest frequency. Sampling errors of the listed potential impediments range from 2 to 8 percentage points at the 95-percent confidence level.

Source: GAO analysis of polling place data collected on Nov. 7, 2000.

**Exhibit E.31: Encountered, or Expect, Difficulties in Voting at a Polling Place
by Disability Status**

	With Disabilities	Without Disabilities
Encountered difficulties, if last voted at polling place since 1990	6%	2%
Would expect difficulties, if haven't voted at polling place since 1990	33%	3%

Source: Schur et al. n.d.

Transportation

(see Exhibits E.32-E.38)

In response to the lack of information about transportation use by people with physical, mental, or emotional disabilities, the Bureau of Transportation Statistics (BTS) initiated the 2002 National Transportation Availability and Use Survey. This survey has not been repeated so it is not possible to measure progress in reducing transportation barriers.

Exhibit E.32: Dimensions of Transportation Reported in Current Surveys

Dimension	Indicator	Grade
Choice	Transportation available in rural or suburban areas, use of paratransit for any trip purpose	F
Spontaneity	Able to make last-minute transportation plans, not required to reserve in advance. Emergency transportation available	F
Aspirations	Number of people with disabilities who own cars equal to those without disabilities	F
Empowerment	People with disabilities able to have a real voice in how transit service decisions are made	F
Quality	Transportation is safe, affordable, reliable, without significant advance reservation	F
Finances	Affordable Transportation. Cost of paratransit the same or similar to regular route transit	F
Satisfaction	Satisfaction with the transportation available to you	C
Inclusion/ Integration	Able to use the same transportation people without disabilities use	C
Public attitudes	Transit staff friendly, helpful, courteous, treat you with respect	F
Accessibility	Bus drivers call out street names. Bus drivers “kneel” the bus or activate the lift for people with mobility disabilities; bus stops and rapid rail accessible	D
Non-discrimination	Transportation with disability or use of wheelchair/dog guide	F
Other	Transportation not just in the city—people want to live outside the city because it’s safer.	F

Satisfaction

- According to the 2002 National Transportation Availability and Use Survey 12 percent of people with disabilities have difficulty getting needed transportation compared to 3 percent of people without disabilities (NTS 2002 reported in Department of Transportation 2003a). A similar gap in satisfaction is revealed in the N.O.D./Harris surveys where 17 percent of people with disabilities reported that transportation was a “major problem” compared to 5 percent of people without disabilities (Exhibit E.33, Harris Interactive 2004).
- In addition to asking if the respondent had difficulty getting needed transportation, the NTS survey ask respondents to cite the type of problem they encountered. One-third cited no or limited public transportation and one-quarter cited the lack of a car (Exhibit E.34, NTS reported in Department of Transportation 2003a). This survey is a valuable source of information. However, unlike other transportation surveys that are repeated annually, this survey was done in 2002 and has not been repeated, so it is not possible to report these statistics longitudinally.
- People with disabilities are more likely than those without disabilities to experience difficulties in long-distance travel at airports, on airplanes, at intercity bus stations, and on intercity buses. They are less likely to experience difficulties at train stations or on trains (Exhibit E.35, NTS reported in Department of Transportation 2003a).
- Based on a survey of 1,000 people as part of a series of monthly surveys fielded by the Bureau of Transportation Statistics (BTS) on different topics, 26 percent of respondents with a disability/health impairment have never flown compared with 16 percent of people without an impairment, based on the Department of Transportation Statistics Omnibus Household Survey in June 2003 (Department of Transportation 2003b).

Inclusion/Integration

Compared to people without disabilities, people with disabilities were much less likely to have driven a car, less likely to be a passenger in a car, and equally likely to have used public transportation in the past month (Exhibit E.36, NTS reported in Department of Transportation 2003a).

Accessibility

The percent of buses that are ADA compliant has increased from 52 percent in 1993 to 98 percent in 2004 (Department of Transportation 2006). This measure is inadequate to assess true access. *The Current State of Transportation for People with Disabilities in the United States*, a 2005 report by the National Council on Disability, highlights many barriers to using public transportation that are not captured by this statistic.

Potential Data Sources

The ACS measures means of transportation to work and travel time to work. It is possible to produce these statistics for people with disabilities but it is not part of the ACS set of standard tabulations.

The National Household Travel survey (NHTS) administered every five years provides vital data on American passenger travel and can be used to examine the relationship among social and demographic change, land development patterns, and transportation. The Federal Highway Administration describes it as “an essential tool for those seriously interested in understanding travel behavior and transportation planning issues.” The survey includes demographic characteristics but does not include a disability indicator.

Exhibit E.33: Percent of Respondents Reporting That Transportation Was a Major Problem or Minor Problem, 1998, 2000, 2004

	1998	2000	2004
Major Problem			
With Disability	17%	16%	17%
Without Disability	7%	4%	5%
Minor problem			
With Disability	13%	14%	14%
Without Disability	10%	6%	8%

Source: Harris Interactive 1998, 2000, and 2004

Exhibit E.34: Difficulty and Type of Difficulty in Getting Transportation, 2002

	With Disabilities	Without Disabilities
Difficulty getting the transportation	12%	3%
Percent citing the following problems		
No or limited public transportation	34%	47%
Don't have a car	26%	23%
Other	26%	23%
Disability makes transportation hard to use	17%	0%
Buses don't run on time	13%	13%
There's no one I can depend on	12%	2%
Don't want to ask for help/inconvenience others	11%	7%
Buses don't run when needed	8%	17%
Bus stops are too far away	8%	10%
Costs too much	7%	4%
No or limited taxi service	5%	6%
Transportation doesn't accommodate special equipment	4%	0%
Fear of crime stops me from going places	1%	5%

Source: U.S. Department of Transportation, Bureau of Transportation Statistics (2003a). Tables 10 and 12.

Exhibit E.35: Percent of People With and Without Disabilities Experiencing Problems with Long-Distance Travel by Location

	With Disabilities	Without Disabilities
At airports	54.5	44.9
On airplanes	32.9	23.6
At intercity bus stations	62.4	17.5
On intercity buses	54.6	22.9
At train stations	23.5	32.6
On trains	12.8	30.6

Source: U.S. Department of Transportation, Bureau of Transportation Statistics (2003a). Tables 10 and 12.

Exhibit E.36: Transportation Modes Used in the Past Month for Local Travel

	With Disabilities	Without Disabilities
Ride in a personal motor vehicle as a passenger	77%	82%
Drive a personal motor vehicle	62%	86%
Walk, including using a non-motorized wheelchair or scooter, on sidewalks, at crosswalks, or intersections	47%	58%
Ride a bicycle or other pedal cycle	18%	34%
Ride on a public bus such as a transit bus or city bus	12%	13%
Take a taxicab	11%	10%
Ride in a carpool or vanpool	11%	14%
Ride on a subway/light rail/commuter train	6%	10%
Use another type of transportation	6%	5%
Use an electric wheelchair, scooter, golf cart, or other motorized personal transportation	6%	3%
Use curb-to-curb transportation provided by a public transportation authority for persons with disabilities (demand responsive service or para-transit service)	6%	2%
Ride on a school bus	5%	11%
Ride on private or chartered bus	5%	6%
Ride on a specialized transportation services provided by human service agencies	4%	2%

Source: U.S. Department of Transportation, Bureau of Transportation Statistics (2003a). Tables 10 and 12.

Exhibit E.37: Percent of Buses That Are ADA Lift-or Ramp-Equipped 1993-2004

Year	Number of Buses	Percent ADA Lift- or Ramp-Equipped
1993	55,726	52%
1994	57,023	55%
1995	57,322	62%
1996	57,369	67%
1997	58,975	69%
1998	60,830	76%
1999	63,618	81%
2000	65,324	84%
2001	67,379	87%
2002	68,418	94%
2003	68,596	95%
2004	68,789	98%

Source: U.S. Department of Transportation, Bureau of Transportation Statistics, (2007).
http://www.bts.gov/publications/national_transportation_statistics/html/table_01_08.html

Housing

The main source of housing data for the general population is the American Housing Survey. The survey asks about physical disabilities but does not include identifiers for any other types of disabilities. HUD has combined the physical disability question with a question about SSI to create a disability indicator that is applicable to the very low income population but other disability populations cannot be identified.

Exhibit E.38: Dimensions of Housing Reported in Current Surveys

Dimension	Indicator	Grade
Choice	Able to choose where and with whom you live, located near things that are important to you; good school system. Accessible, affordable housing in safe areas	F
Spontaneity	Able to visit neighbors and friends in their homes (visitability)	F
Aspirations	Number of people with disabilities who own homes equal to those without disabilities	C
Quality	Safe, affordable, accessible housing with access to shopping, services and transportation Condition of home	F
Finances	Affordable housing, given your income. Own your own home. If you own, able to afford or get assistance to make the modifications needed	D
Satisfaction	Satisfaction with your housing arrangements	F
Inclusion/ Integration	Live in a neighborhood or building with people who do not have disabilities	D
Assistance and Support	Assistance and support you need to live independently; variety of housing options to meet various needs for independence; informal support from family/friends to enable independence	F

(Continued)

Exhibit E.38: Dimensions of Housing Reported in Current Surveys (cont.)

Public attitudes	Neighbors treat you with respect, friendly, include you in neighborhood activities	F
Accessibility	Housing unit accessible to you. Located near the transportation, shopping, and community services you need	F
Non-discrimination	No discrimination in looking for a place to live	F
Safety/Risk	Accessible, affordable housing in safe areas	F

Finances

- In 1998 the amount of income needed to rent a modest one-bedroom unit was 69% of the monthly SSI check. In 2004, the amount needed had risen to 110% of the SSI check amount. An analysis of all 2,708 housing market areas found that in 2004 there was not one area in the United State with rents affordable to SSI recipients (Units are considered affordable if they cost 30% or less of an individual's income), (O'Hara and Cooper 2005).
- Based on data from the 2005 American Housing Survey (AHS), 4.5 percent of the vacant rental units would be affordable for a single individual with income at the poverty level.
- Of the estimated 53.9 million people with disabilities, less than half (i.e., 48%) either own or rent their own homes. Instead, they live in someone else's home or in an institutional setting (1994–95 SIPP reported in Klein and Nelson 1999).
- Between 1997 and 1999 the number of families with “worst case housing needs,” defined as being very low income and spending more than 50 percent of their income on housing cost, declined among all groups except the elderly and people with disabilities. In 1999, at least 22 percent of worst case households had nonelderly adults with disabilities (AHS using a constructed proxy for disability reported in Department of Housing and Urban Development 2003—see AHS in appendix B for description of proxy).

Accessibility

- There are no national data sources on housing accessibility. In its 2005 Fair Housing Report, the U.S. Department of Housing and Urban Development reported that at least one-third of the advertised rental properties in the Chicago area were not accessible to wheelchair users based on a study of that market (HUD 2005).
- As for the state of repair of housing for people with disabilities, data from the American Housing Survey shows that although only 8.7% of the total units are occupied by

families that get SSI or other disability income, and those families have 29 percent of the homes with moderate to severe physical problems (2005 AHS reported in Census Bureau 2006).

Discrimination

The 2005 Fair Housing Report cited above reports that the number of complaints for disability discrimination for the first time surpassed race discrimination as the most common allegation in complaints. Disability discrimination complaints accounted for about 41% of the complaints filed with HUD and local Fair Housing Assistance agencies.

In July 2005, HUD issued the fourth phase of its Housing Discrimination Study—*Discrimination Against Persons with Disabilities: Barriers At Every Step*. The study examined the Chicago area rental market and found that hearing-impaired persons, using a telephone-operator relay to search for rental housing, experienced consistent adverse treatment almost 50 percent of the time. The study also found that mobility-impaired persons using wheelchairs experienced consistent adverse treatment 32 percent of the time when they visited rental properties. It is important to note that HUD found that the discrimination was often subtle enough that individuals would not know that they were discriminated against unless they were able to compare the information that they received with the information received by a paired tester who did not have a disability. The information differed in such a way as to discourage the individual with a disability from further pursuing a lead for a rental or purchase.

Choice

- The number of adults with disabilities (age 22 and over) living in congregate care facilities has declined from 93,362 in 1997 to 65,575 in 2005 (Survey of State Developmental Disabilities Directors, University of Minnesota reported in *Healthy People 2010*).

Potential Data Sources

The ACS measures the percent of people that move within the same county, from a different county within the same state, from a different state, or from abroad (geographic mobility). This could be used as a proxy for choice in housing and community. It is possible to produce these statistics for people with disabilities but it is not part of the ACS package of preproduced tables.

The ACS asks, “Is this house, apartment, or mobile home: a) Owned by you or someone in this household with a mortgage or loan? b) Owned by you or someone in this household free and clear (without a mortgage or loan)? c) Rented for cash rent? d) Occupied without payment of cash rent?” *The Disability Statistics Reports* report that 63 percent of people with disabilities answered a) or b) to this question compared to 70 percent of people without disabilities. Although home ownership was noted as an aspiration in our focus group, this data is not a good measure because it does not allow the data user to distinguish between a home owned by a person with a disability and a home owned by someone else in the household such as a parent, sibling, or friend.

The Decennial Census collects enough information to be able to calculate the percent of people with disabilities who live in high poverty neighborhoods. In 2000, 16 percent of the US population lived in neighborhoods with poverty rates between 20 and 40 percent of FPL, and 3 percent lived in neighborhoods with more than 40 percent of the residents in poverty (Bishaw 2005). This statistic is calculated by state, by age, and by race, but it is not calculated by disability. This could be an important indicator because it is well established that in these neighborhoods, crime and violence are common, jobs are scarce, schools are often under-funded, and young people see few opportunities for success. An extensive and growing body of social science research indicates that living in these high-poverty communities undermines access to mainstream social and economic opportunities (Turner and Rawlings 2005).

Personal Relationships

(see Exhibit E. 39-E.40)

There are few resources that provide information about personal relationships for people with disabilities; it is therefore particularly surprising that two data sources—the National Survey of Family Growth and the National Survey of Families and Households—have not been tapped. Both have disability indicators, both have sample sizes large enough to support an analysis of people with disabilities, and both have important measures of personal relationships.

Exhibit E.39: Dimensions of Personal Relationships Reported in Current Surveys

Dimension	Indicator	Grade
Choice	Choice in marriage and children	C
Spontaneity	Able to make last minute plans with friends or family; e.g., transportation, personal assistance	F
Aspirations	Aspire to marriage and children	F
Empowerment	Feel comfortable disclosing or discussing your disability with family and friends	F
Quality	Close, egalitarian, empowering relationships with friends and family	F
Finances	Have enough money to go out with your friends	F
Satisfaction	Satisfaction with number and types of personal relationships	F
Inclusion/Integration	Able to choose to have relationships with people with and without disabilities	F
Assistance and Support	Service agencies that help you find social relationships if needed (peer groups or recreation activities)	F
Public attitudes	Feel comfortable disclosing or discussing your disability to friends and family	F
Non-discrimination	Abuse, neglect, or mistreatment by family, friends, or assistants	F
Safety/Risk	Know how to deal with abuse when it happens	F

In 2004, 79 percent of people with a disability socialized with close friends, relatives, or neighbors at least once per week (Exhibit E.40, Harris Interactive 2004). The N.O.D./Harris survey has included this measure since 1986. In every year, people with disabilities were less likely to have socialized once a week or more. The disparity between people with and without disabilities ranges from 10 to 15 percentage points. There is no clear trend in either the percent of people with disabilities socializing or in the disparity with people without disabilities.

Exhibit E.40: Percent of Adults Who Socialize With Close Friends, Relatives, or Neighbors At Least Once a Week by Disability Status and Data Year: United States, 1986-2004

Disability status	1986	1994	1998	2000	2004
No disability	85	86	84	85	89
Any disability	75	69	70	70	79

Source: Harris Interactive 2004

Potential Data Sources

There are several potential sources of data to measure personal relationships.

Behavioral Risk Factor Surveillance System (BRFSS). The BRFSS is conducted annually by each of the U.S. States according to standardized guidelines and under the general direction of the Centers for Disease Control and Prevention. Data is collected by telephone from randomly selected sample adults in each state. Sample sizes vary, but typically are in the 2,000 to 4,000 range. There is a Core questionnaire that must be used by every state, optional standardized topical questionnaires, and *ad hoc* supplementary questions that any state may add.

Since 2001, the Core questionnaire has included two questions that identify persons with disabilities, which means that beginning with that year it is possible to make annual estimates of any measure of interest that is included in the annual BRFSS Core questionnaire, and for other measures for selected states and years. In 2006, the Core

included, for the first time, a question on social and emotional support—“How often do you get the social and emotional support you need? Always, Usually, Sometimes, Rarely or Never?”

Questions on the Core questionnaire are of three types: annual, periodic, and “emergent.” Annual questions are included every year, periodic questions are included regularly but with a longer periodicity, and emergent questions may or may not be repeated. The BRFSS disability questions are annual. The status of the social and emotional support question is not clear. If it becomes annual or periodic it could be used to create a time series of estimates of a measure of interpersonal relationships for persons with and without disabilities.

The measure would have the advantages of being based on a large, national sample that also can make estimates for each state. Its disadvantages include its being based on a telephone survey and that it would not have a regular publication outlet—that is, CDC does not publish an annual report that would include this statistic, although that might be arranged.

National Health and Nutrition Examination Survey Sample Person Questionnaire (NHANES). Beginning in 2001, NHANES has included in its “sample person” questionnaire, some questions on “social support” which can be taken as measures of personal relationships. The Sample Person questionnaire is administered face-to-face in the homes of sample families. The survey asks the following questions: 1) Can you count on anyone to provide you with emotional support such as talking over problems or helping you make a difficult decision? 2) [In the last 12 months], could you have used more emotional support than you received? 3) [If yes] Would you say that you could have used a lot more, some, or a little more emotional support? 4) In general, how many close friends do you have?

NHANES also has measures of disability. Statistics for these measures would be based on a large sample, and would be available for each year (although the data are released in two-year batches). A disadvantage is that the questions are asked only of sample

persons who are 40 years of age or older. Also, there do not appear to be regularly scheduled reports that would include estimates of these statistics for persons with and without disabilities, although it would not be difficult or costly to produce such reports.

Survey of Income and Program Participation (SIPP). Most large national surveys routinely gather information on the living arrangements and marital status of sample persons. These can be regarded as measures of personal relationships, and if the survey also gathers disability identifiers, estimates could be made for persons with and without disabilities. Regrettably, although several large national surveys have this capability, they do not, for the most part, report them regularly. For instance, in the annual NHIS table of characteristics of persons classified by disability status, neither marital status or living arrangement is included, although it could be added at little cost. SIPP is an exception because it has published some data on living arrangements: for instance, a report based on the 2002 SIPP found that among persons 25-64 years of age, 67.6 percent of persons with no disability were living in a married couple family, while among persons with severe disabilities only 50.1% were in married couple families. Unfortunately, SIPP is being discontinued for budgetary reasons. Similar data are collected by the American Community Survey, and could be used to produce these measures of personal relationships on an annual basis.

Sexual relationships: NSFG, NHANES, and BRFSS. The National Survey of Family Growth (NSFG) collects a substantial amount of information about sexual behavior that could be used to measure this type of personal relationship among persons with and without disabilities. In its 2003 cycle, the NSFG added disability screening questions for the first time. Beginning in 2006 the NSFG became a continuous data system, so that it could produce such estimates every year or two. The NSFG is limited, however: it covers only persons of reproductive age (15-44 years) and its sample is relatively small. NHANES and BRFSS also collect some information on sexual behavior and could produce estimates for persons with and without disabilities.

National Survey of Families and Households (NSFH). The NSFH is a longitudinal survey that was administered three times—1987–88, 1992–94, and 2001–2003. It started

with a sample of 13,000 households and included 9,000 households in the most recent survey cycle. It includes an oversample of racial and ethnic minorities but not people with disabilities. It is a rich source of information about family structure, relationships, satisfaction with friendships, family life, employment, and amount of leisure time. It asks the respondent to assign a level of agreement to interesting subjective statements including for example, "I feel that I'm a person of worth, at least on an equal plane with others." Only a limited number of standard tables are produced and none of them include disability. As far as we know, no researchers have analyzed the data for people with disabilities.

Technology

(see Exhibit E.41)

Much of the research on the use of technology by people with disabilities focuses on Assistive Technology (AT), which is specifically designed to increase, maintain, or improve the functional capabilities of individuals with disabilities. Other research, however, looks at access to off-the-shelf technology, often emphasizing the role that Universal Design can play regarding the accessibility of technology to individuals with various types of disabilities.

Exhibit E.41: Dimensions of Technology Reported in Current Surveys

Dimension	Indicator	Grade
Choice	Choice among a number of off-the-shelf and assistive devices	F
Spontaneity	Ease of making a cell phone call to connect or make last minute plans	F
Empowerment	Knowing how to use or obtain assistance with off the shelf or assistive technology	F
Finances	Can afford to buy needed technology or have it covered by a third party	F
Satisfaction	Satisfaction with access to and usability of technology	F
Assistance and Support	Adequate training and technical assistance in using technology	F
Public Attitudes	Technical support people have basic knowledge of assistive technology	F
Accessibility	Off-the-shelf technology and appliances are accessible; internet and web site access	C

Much of our knowledge about assistive devices is quite dated—it comes from the 1994 National Health Interview Survey on Disability (NHIS-D). That survey found that the use of assistive devices had increased dramatically from 1980 to 1994. (Use of braces, walkers and wheelchairs all more than doubled.) More people (7.4 million in 1994) used AT to compensate for mobility impairments than any other type of impairment. Hearing aids (4.2

million) and back braces (1.7 million) were also commonly used. Regardless of the type of assistive device, usage increased with age. Thus, among those persons using assistive devices, those over 65 years of age accounted for the majority of mobility, hearing, and vision device usage. Some assistive device usage also increased at a rate faster than expected given changes in population size and age composition (Russell et al. 1997).

Estimates from the NHIS-D indicated that, in 1994, of 41.8 million Americans with disabilities aged 18 years and older:

- 40 percent used special equipment to perform basic activities of daily living or used assistive devices such as tracheotomy tubes, diabetic equipment, crutches, walkers or feeding tubes.
- 34 percent lived in homes modified to meet their special needs. 6 percent said they needed modifications that they didn't have.
- Of the 15.1 million Americans with disabilities who were working at the time of the interview, 7 percent said that they had accommodations provided and/or their workplaces had accessibility modifications. However, 12 percent said that they needed accommodations or accessibility modifications.

In a 2001 survey, Carlson et al. (2002) screened a total of 1,551 households to identify those with one or more members with a disability. Screening questions were similar to those used in the 2000 Census. From this screening, 315 households (20 percent) were identified as having at least one member with a disability. A total of 269 persons provided survey results, reflecting a response rate of 85 percent. None of the questions asked directly if the respondents with disabilities used AT devices; rather, they asked questions concerning access to information about devices and the helpfulness and need for devices. Those results for usefulness and need were:

- 42 percent of the respondents thought that AT devices and services had decreased their need for help from another person "some" or "a lot". (The other choices were "a little" and "none".)

- 52 percent of the respondents thought that better designed products and environmental access features reduced the need for AT devices and services "some" or "a lot."

In a national survey of 1,412 individuals with disabilities, Carlson and Ehrlich (2005) asked the 901 individuals who used some sort of AT how they found out about the technology they were using. The most mentioned source was a physician or other health care professional (53%). The only other sources mentioned frequently were family and friends (15%) and vocational rehabilitation counselors (13%). Those who cited family and friends as the source of their information were less satisfied with both the information and the helpfulness of the technology.

The 2001 survey by Carlson et al. cited above found that while 90 percent of the respondents had a general awareness about the availability of AT-related information and assistance, only 40 percent said they had actually obtained some type of AT-related information that might be useful to themselves.

Funding

A 2001 national survey of AT users found that the most mentioned payment source for AT devices was self or other family member in the household (Carlson and Ehrlich 2006).

Potential Sources of Data

The CPS has a core survey and monthly supplemental surveys. The work disability question (do you have a health problem or disability which prevents you from working or which limits the kind or amount of work you can do) is asked on the March supplement. Every two years, another supplement includes questions about computer ownership, internet access, and internet use. In order to calculate the computer technology use of people with disabilities compared to those without disabilities, an analyst needs to merge the two supplements. However, because of the sampling frames, only about one-third of the people in the March Supplement will be asked the question from the other supplement. As far as we know, the sample size is large enough to perform the

analysis, but it has not been done in the past 5 years, and earlier analysis is out of date given the dramatic changes in the use of computer technology.

Appendix F: PART Outcome Measures

Appendix F lists the outcome measures in the PART evaluations of 40 programs, half of which serve only people with disabilities and half of which serve people with disabilities within a broader population. We reviewed these measures to ascertain whether the PART program evaluation includes factors important to focus group participants. We found that the two types of programs had significant limitations in how outcomes for people with disabilities are measured and that most only minimally reflect meaningful quality of life for people with disabilities.

Education

Federal Support for Gallaudet University

Federal funding for Gallaudet helps promote educational and employment opportunities for persons who are deaf. Gallaudet offers liberal arts programs for baccalaureate and graduate students. It also operates elementary and secondary education programs and conducts research related to deafness.

- The percentage of first-time, full-time undergraduate students and all graduate students eligible to return in one academic year who are enrolled the following academic year.
- The graduation rate for graduate and the Model Secondary School for the Deaf (MSSD) students.
- The percentage of graduates with baccalaureate degrees who are employed, in advanced education or training, or are neither employed or enrolled in advanced education or training during their first year after graduation.
- The percentage of full-time, first time baccalaureate students who have graduated within six years and the ratio of students who graduate each year to the number of students entering six years prior.

- The percentage of Model Secondary School for the Deaf (MSSD) graduates who are employed, in postsecondary education or training, or not employed or in postsecondary education or training during their first year after graduation.
- The number of programs and/or institutions adopting innovative curricula and other products or modify their strategies as a result of Model and Kendall school leadership will be increased.

Federal Support for the National Technical Institute for the Deaf—DOE

Federal funding for the National Technical Institute for the Deaf promotes educational and employment opportunities for persons who are deaf. The Institute offers a variety of technical programs and supports students who are deaf in obtaining higher-level degrees from the Rochester Institute of Technology.

- The percentage of sub-baccalaureate who graduate within three years and baccalaureate students who graduate within seven years.
- The percentage of graduates who are employed, in advanced education or training, or are neither employed or enrolled in advanced education or training during their first year after graduation.
- The percentage of sub-baccalaureate students and first-year baccalaureate students who are freshman and first-year transfers who are enrolled the following academic year.
- The post-school rate of National Technical Institute for the Deaf graduates who are not engaged in either advanced education or training or in the workforce during their first year after graduation.
- The post-school rate of National Technical Institute for the Deaf graduates who are in advanced education or training during their first year after graduation.

Employment and Training

All employment and training programs are evaluated by the Job Training Common Measures in addition to any outcomes specified by the agency. The Common Measures are:

- Entered Employment—Percentage employed in the first quarter after program exit.
- Retention in Employment—Percentage of those employed in the first quarter after exit that were still employed in the second and third quarter after program exit.
- Increase in Earnings—Percentage change in earnings: (i) pre-registration to post program; and (ii) first quarter after exit to third quarter.

Vocational Rehabilitation State Grants

This program supports vocational rehabilitation services through assistance to the States. State vocational rehabilitation agencies provide a wide range of services designed to help persons with disabilities prepare for and engage in gainful employment to the extent of their capabilities.

- Percent of State VR agencies (excluding VR agencies for the Blind) that assist at least 55.8 percent of individuals receiving services to achieve employment.
- Percent of State VR agencies (excluding VR agencies for the Blind) that assist at least 85 percent of individuals with employment outcomes to achieve competitive employment (employment in an integrated setting at/or above the minimum wage).
- Percent of State VR agencies (excluding agencies for the Blind) for which at least 80 percent of the individuals achieving competitive employment are individuals with significant disabilities. The criterion in 2005 was increased to reflect more ambitious targets.

Vocational Rehabilitation and Employment Program—Veterans

The program enables veterans with service-connected disabilities to obtain suitable employment or achieve independence in daily living. Counselors conduct a

comprehensive evaluation of the veteran's vocational rehabilitation needs and provide individualized services such as job placement, training, and adaptive equipment.

- Rehabilitation Rate (rehabilitated versus discontinued).
- Serious Employment Handicap Rehabilitation Rate.
- Percent of participants employed first quarter after program exit.
- Percent of participants still employed three quarters after program exit.
- Rehabilitation Planning Rate (Percent found entitled to VR&E services who actually sign a rehabilitation plan and pursue services).
- Customer Satisfaction (Survey).
- Percent change in earnings from pre-application to post-program.

Projects with Industry for People with Disabilities

This program aims to create and expand job opportunities in the competitive labor market for individuals with disabilities while engaging private industry as a partner in the rehabilitation process.

- Average increase in weekly earnings of participants placed into competitive employment.
- The percentage of individuals served who are placed in competitive employment.
- Percentage of previously unemployed individuals served who were placed in competitive employment.
- The percentage of participants exiting the program who are placed in competitive employment.
- The percentage of Projects With Industry projects who demonstrate an average annual cost per participant within a specified range (new measure, added February 2007).

Work Incentive Grants (DOL)

The purpose of this Department of Labor program is to test ways to increase the labor force participation and career advancement of persons with disabilities. The program uses competitive grants to enable the nationwide network of local One-Stop Career Centers better serve those job seekers.

- Exiters with disabilities
- Entered Employment
- Employment Retention
- Wage Gain

Office of Disability Employment Policy (DOL)

The Office of Disability Employment Policy works to address the significant barriers to employment faced by individuals with disabilities. It conducts research, shares effective strategies, and provides technical assistance to increase the employment opportunities of people with disabilities.

- Policy related documents disseminated
- Formal agreements initiated
- Effective practices identified

Other Employment and Training Programs that Serve People with Disabilities

Employment Service (DOL)

Employment Service grants support basic employment services and workforce information for job seekers and employers. Services are delivered through a nationwide network of One-Stop Career Centers and Internet-based tools. Services include labor market and career information and job matching.

- Percentage of participants employed after program exit.
- Percentage of participants who retain employment found after program exit.

- Earnings of those who are employed in the first, second, and third quarters after the exit quarter.

Health Care

Programs for People with Disabilities

Mental Health Programs of Regional and National Significance

Mental Health Programs of Regional and National Significance seeks to improve mental health care delivery systems in the United States. The program administers grants and contracts to help identify evidence-based and recovery-based service models, and provides assistance in applying them in communities

- Average number of evidence-based practices implemented per State and percentage of service population coverage for each.
- Percentage of people in the United States with Serious Mental Illnesses in need of services from the public mental health system, who receive services from the public mental health system.
- Client functioning (developmental)
- Rate of consumers/family members reporting positively about outcomes (Program participants).
- Rate of consumers/family members reporting positively about outcomes (State mental health system).

Programs with special eligibility categories for people with disabilities

Medicaid-HHS/CMS

Medicaid is a means-tested, Federal-State funded entitlement program that provides medical assistance, including acute and long-term care, to families with dependent children as well as aged, blind, or disabled individuals. The Centers for Medicare and Medicaid Services (CMS) provides Federal oversight of this program.

- Percentage of beneficiaries who receive home and community-based services.

- Prevalence of Restraints in Nursing Homes (proxy for quality of care in nursing homes).
- Percentage of States for which CMS makes a non-delivery deduction from the State's subsequent year survey and certification funds (proxy for CMS oversight of quality in nursing homes and home and home health agencies).
- Medicaid Integrity Program, Percentage Return on Investment (measure of fraud, waste, and abuse).

Medicare

Medicare finances health insurance for eligible elderly and disabled individuals. As of January 1, 2006, the Medicare benefit includes outpatient prescription drug coverage.

- Protect the Health of Medicare Beneficiaries by Optimizing the Timing of Antibiotic Administration to Reduce the Frequency of Surgical Site Infection.
- Maintain CMS' Improved Rating on Financial Statements.
- Percent of Medicare beneficiaries receiving influenza vaccination; pneumococcal vaccination.
- (1) Number of questions about Medicare out of 6 answered correctly; (2) Percentage of Medicare beneficiaries who are aware of the 1-800-MEDICARE toll free number.
- Percent of women who receive a biennial mammogram.
- Percent of diabetic beneficiaries who receive diabetic eye exams.
- Reduce the Medicare Contractor Error Rates.
- Percent of beneficiaries in (1) managed care and (2) fee-for-service who report access to care; access to specialist. Develop MMA survey for FY 2006/2007.
- Improve the care of diabetic beneficiaries by increasing the rate of hemoglobin A1c and cholesterol (LDL) testing.

Veterans Medical Care

This medical care system provides health care services to eligible veterans. The program provides most services through a nationwide network of medical centers and clinics.

- Clinical Practice Guideline Index.
- Percent of Patients Rating VA Health Care Service as Very Good or Excellent (Outpatient).
- Increase the Scores on the Prevention Index II.
- Percent of Specialty Care Appointments Scheduled Within 30 days of the Desired Date.
- Percent of Primary Care Appointments Scheduled Within 30 days of the Desired Date

Other Health Care Programs that Serve People with Disabilities

Chronic Disease—Breast and Cervical Cancer, Dept. of Health & Human Service, CDC

The Breast and Cervical Cancer program provides access to critical screening services for underserved, low-income women who have little or no health insurance coverage for these services. It provides grants to state health departments for breast and cervical cancer screenings.

- Percentage of all newly enrolled women who have not received a Pap test within the past five years.
- Percentage of women with abnormal results who receive a final diagnosis within 60 days of screening.
- Percentage of women with breast cancer and cervical cancer who start treatment within 60 days of diagnosis.

Chronic Disease—Diabetes

The Centers for Disease Control and Prevention Diabetes program helps to eliminate the preventable burden of diabetes through leadership, research, programs, and policies that translate science into practice. The program supports state health departments that focus on reducing the health complications caused by diabetes.

- Rate of lower extremity amputations in persons with diabetes.
- Percentage of people with diabetes who receive the recommended eye and foot exams in States with comprehensive diabetes control programs funded by the program.
- Percentage of persons with diabetes who receive at least 2 blood sugar control measures per year in States with comprehensive diabetes control programs funded by the program.

Chronic Disease Prevention

The purpose of the program is to: prevent death and disability due to chronic diseases and promote healthy personal behaviors across the entire life span. The program accomplishes these goals in partnership with health and education agencies, major voluntary associations, the private sector and other federal agencies.

- Age-adjusted annual rate of breast cancer mortality per 100,000 female population.
- Age adjusted rate of invasive cervical cancer per 100,000 women ages 20+ screened through the NBCCEDP (excludes invasive cervical cancers diagnosed on the initial program screen).
- Age-adjusted annual rate of trachea, bronchus, and lung cancer mortality per 100,000 population.
- Proportion of children aged 3 to 11 who are exposed to second-hand smoke.
- Age-adjusted annual rate per 100,000 population of coronary heart-disease and stroke-related deaths.

- Estimated average age-adjusted annual rate of increase in obesity rates among adults age 18+.
- Percentage of women age 40+ who have had a mammogram within the previous two years. Per capita cigarette consumption in the U.S. per adult age 18+.
- Age-adjusted percentage of persons with diabetes age 18+ who receive an A1C test at least two times per year.
- Age-adjusted proportion of persons age 18+ with high blood pressure who have it controlled (<140/90).
- Age-adjusted proportion of persons age 20+ with high total blood cholesterol (≥ 240 mg/dL).
- Age-adjusted percentage of adults age 18+ who engage in no leisure-time physical activity. Percentage of youth (grades 9 through 12) who were active for at least 60 minutes per day for at least five of the preceding seven days.

Health Centers

This program provides grants to health centers to provide medical care to uninsured, underserved, and vulnerable populations in rural and urban areas. In 2005, 3,745 health centers provided care to over 13 million people.

- Number of new or expanded sites and total persons served.
- Number in millions of those served by health centers who are below 200% of poverty and the national percentage of all people below 200% of poverty served by the program.
- Number of new and expanded health center sites.
- Reduce low birth weight rates in health centers to 6.53%, consistent with the *Healthy People 2010* goal.

Indian Health Service Federally-Administered Activities

The purpose of the Indian Health Service is to improve the health status of American Indians and Alaska Natives. Through its Federally-administered activities, the Indian Health Service provides clinical and preventive health services directly and through purchasing from the private sector.

- Years of Potential Life lost in American Indian/Alaska Native population.
- Children ages 2-5 years with a BMI of 95% or higher.
- Unintentional injury mortality rate in American Indian/Alaska Native population.
- Number of hospitalizations for long-term complications among patients with diabetes in direct facilities.

Injury Prevention and Control

Collaborating with numerous organizations and agencies, the program promotes and supports research into the causes and prevention of unintentional and violence-related injuries and to improve injury response and treatment. Priorities include falls, fires, child maltreatment, and traumatic brain injury.

- Reduce by 10% homicide rates among youth aged 15–24 in NVDRS states with FY 2003 baseline data.
- Reduce youth homicide rate by 0.1 per 100,000 annually.
- Impact self-reported victimization of youth as measured by reductions in 2 of 3 of the following: unwanted sexual intercourse, dating violence, and physical fighting.
- Reduce victimization of youth enrolled in grades 9–12 as measured by a reduction in the lifetime prevalence of unwanted sexual intercourse, the 12-month incidence of dating violence, and the 12-month incidence of physical fighting.
- Among the states receiving funding from CDC, reduce deaths from residential fire to 1.02 per 100,000 population.

- Among states receiving funding from CDC, reduce deaths from residential fires by 0.01 per 100,000.
- Achieve an age-adjusted fall fatality rate among persons age 65+ years of no more than 69.6 per 100,000.
- Decrease the estimated percent increase of age-adjusted fall fatality rates among persons age 65+ years.

Office of Disease Prevention and Health Promotion

The Office of Disease Prevention and Health Promotion provides leadership, coordination, and policy development for public health prevention activities. It focuses national attention on prevention issues by keeping Americans informed of ways to reduce their risk of disease and increase years of healthy life.

- Awareness of Dietary Guidelines for Americans for the general population.
- Increase the percentage of *Healthy People 2010* objectives that have met the target or are moving in the right direction. (New measure, February 2007).

Housing

Programs Specifically for People with Disabilities

Housing for Persons with Disabilities—HUD

This program provides construction grants, operating subsidies, and housing vouchers for very low-income persons with disabilities. It is limited to non-profit organizations who own and operate the housing.

- Number of households including a disabled person with worst-case housing needs (in thousands) These households do not receive Federal assistance but have incomes below 50 percent of the local median, and pay more than half of their income on rent or live in poor quality housing.

Housing Opportunities for Persons with AIDS—HUD

Housing Opportunities for Persons with AIDS (HOPWA) provides housing and supportive services for low-income individuals living with HIV or AIDS. Ninety percent of funds are distributed to states and localities through a block grant formula, and ten percent of funds are distributed through a national competition.

- 80% of HOPWA clients will maintain housing stability, avoid homelessness, and access care each year through 2011.
- Number of households receiving HOPWA housing assistance during a given year.

Projects for Assistance in Transition from Homelessness—HHS/SAMHSA

Projects for Assistance in Transition from Homelessness makes grants to States to provide outreach, mental health and other support services to homeless people with serious mental illness. Outreach is focused on homeless individuals who are not pursuing needed mental health treatment on their own.

- Percentage of enrolled homeless persons who receive community mental health services

- Percentage of contacted homeless persons with serious mental illness who are enrolled in services

Other Housing Programs that serve people with disabilities

Fair Housing Assistance Program—HUD

The Fair Housing Assistance Program helps protect people who believe they have been victims of discrimination. To enforce fair housing laws, formula grants are awarded to participating state/local law enforcement agencies for activities including capacity building, complaint processing, enforcement efforts and training.

- Percentage of consistently unfair treatment towards minorities (blacks, Hispanics, and Asians) over whites in paired testing for rental and sales housing markets
- Percentage of the general public who can correctly identify six or more of the eight scenarios describing illegal conduct as unlawful
- Average percentage of multifamily projects in the field that conform to the seven design and construction requirements of the Fair Housing Act

FHA Multi-Family Mortgage Insurance—HUD

The program enhances credit for rental housing developments through the provision of Federal loan guarantees. These guarantees provide a financing option in addition to those available in the private conventional market.

- Expand Access to affordable private market housing (no specific measure identified in PART). Among households living in multifamily properties, the share living in developments that have substandard financial management decreases by 2.5 percent per year.
- The number of multifamily rental units in underserved areas newly insured by FHA increases by 5 percent.
- The share of housing units that meet HUD's physical standards will exceed 92% by FY 2005.

- For Households living in assisted and insured privately-owned multifamily properties, the share that meet HUD's financial management compliance is maintained at no less than 95 percent.
- The average number of Exigent Health and Safety or Fire Safety Deficiencies per property does not exceed 2.10 for multifamily housing.
- The share of assisted and insured privately owned multifamily properties that meet HUD established physical standards are maintained at no less than 95%.
- The share of multifamily properties in underserved areas insured by FHA is maintained at 25 percent of initial endorsements.

FHA Single-Family Mortgage Insurance—HUD

The Federal Housing Administration (FHA) insures private FHA-approved lenders against losses from default on single-family mortgages they issue. The program's purpose is to expand homeownership opportunities for first-time and minority homebuyers.

- The ratio of minority and non-minority low- and moderate-income families with children increases by 0.4 percentage points annually.
- The share of first-time minority homebuyers among FHA home purchase-endorsements.
- The percentage of loans at risk that have been reviewed and determined to have findings.
- The percentage of foreclosed loans or at risk loans to the total number of loans two years after origination.

Homeless Assistance Grants —HUD

Homeless Assistance Grants provide housing and supportive services to homeless families and individuals across the country. Funds are competitively awarded to

localities and nonprofits through a coordinated community-based process of identifying and addressing the needs of the community.

- By 2009, 65 percent of households leaving transitional housing will directly move to permanent housing.
- Within the next five years (2005–2009), HUD will create 20,000 new units of permanent housing for chronically homeless individuals.
- The percentage of formerly homeless persons who remain housed in HUD permanent housing projects for more than 6 months will be 70 percent in 2005, and will increase one percent each year.
- The percentage of homeless persons who have moved from HUD transitional housing into permanent housing will be 60 percent in 2005, and will increase one percent each year.
- In 2005, the employment rate of persons exiting HUD homeless assistance projects will be 10 percentage points greater than the employment rate of those entering, and will increase one percent each year. (Note: This measure is being revised to more accurately reflect the employment rates of everyone exiting projects. For example, in 2005, 10% of entrants were employed and 17% were employed upon exiting the program.)

Homeownership Voucher—HUD

The Homeownership Voucher program was added in 2001 as a new component of the Housing Choice Voucher program, which has traditionally been for rental assistance, to allow families in HUD rental assistance programs to use their Voucher for mortgage payments or down payments.

- The 2006 long-term performance goal is to create 20,000 new homeowners in ten years (from 2006–2016).
- Number of homeownership closings.
- By 2010, the default rate will remain at or below the national average.

Housing Vouchers—HUD

The Housing Choice Voucher Program assists 2 million low-income households across the country afford housing. The program purpose is to help these families afford decent, safe and sanitary housing. Tenants, who would otherwise pay over 50% of their income to rent an apartment on the private market, pay 30% of their income.

- Number of Housing Choice Voucher households that have accumulated financial savings through the Family Self-Sufficiency program.

Income Support

Programs Specifically for People with Disabilities

Social Security Programs (Social Security Disability Insurance, Supplemental Security Income)—SSA

Social Security Disability Insurance program pays benefits to persons who are unable to earn a living due to a disability. The program also provides money to their dependents. Benefits are based on the disabled person's lifetime average earnings.

- Initial disability claims average processing time (days) (DI & SSI Blind and Disabled). This is the number of days from the filing of an application to the date processing is complete.
- Average processing time for hearings (in days).

Veterans Disability Compensation—VA

This program provides monthly benefit payments to veterans who suffer from diseases or disabilities related to their military service. Disabled veterans are assumed to earn less in civilian occupations than non-disabled veterans and these payments are provided to make up for this difference.

- Percent of veterans in receipt of compensation whose income exceeds that of like-circumstanced veterans.
- Percent of compensation recipients who were kept informed of the full range of available benefits.
- Percent of compensation recipients who perceive that VA compensation redresses the effect of service connected disability in diminishing the quality of life
- National Accuracy Rate—core rating work
- Rating related actions—average days pending
- Authorization—Accuracy Rate
- Overall Satisfaction Rate

- Out of all original claims filed within the first year of release from active duty, the percentage filed at a Benefits at Delivery Discharge (BDD) site prior to a service members discharge.

Veterans Disability Pension—VA

This program administers disability benefits to lower-income veterans who are either permanently and totally disabled from injury or disease not related to service or who are 65 or older, and their survivors. The program's purpose is to assure a level of income which allows beneficiaries to live in dignity.

- Percent of recipients who were informed of the full range of available benefits.
- Percent of VA beneficiaries receiving financial assistance for medical expenses.
- Percent of pension recipients who believe that the processing of their claim reflects the courtesy, compassion, and respect due to a veteran.
- National Accuracy Rate-Authorization Work
- Overall satisfaction rate
- Rating—average days pending
- Percent of recipients who said their claim was very or somewhat fair.
- Rating—accuracy rate

Black Lung Compensation—DOL/Employment Standards Administration

The purpose of this program is to provide wage-replacement and medical benefits to coal miners who are totally disabled due to pneumoconiosis (black lung disease) and to eligible survivors.

- Percentage of Black Lung benefit claims decided under the revised regulations where there are no requests for further action from any party pending one year after receipt of claim.

- Average number of days for the Office of Workers' Compensation Programs to render a decision on a claim for Black Lung benefits.

Longshore and Harbor Workers' Compensation Program—DOL

This program provides wage-replacement, medical, and vocational rehabilitation benefits to eligible injured workers or their survivors. It also adjudicates disputed claims and ensures that employers and insurance carriers pay benefits in a timely manner.

- Percentage of individuals completing rehabilitation plans who return to work within 6 months of plan completion

Other Income Support Programs that Serve People with Disabilities

Temporary Aid to Needy Families—HHS

The program provides time-limited cash assistance to needy families with children while working toward achieving the goals of ending dependence by promoting work and marriage, preventing out-of-wedlock births, and encouraging the formation and maintenance of two-parent families.

- Increase (from the baseline year) the percentage of adult TANF recipients who become newly employed.
- Increase (from the baseline year, FY2000) the percentage of adult TANF recipients/former recipients employed in one quarter of the year that were still employed in the next two consecutive quarters.
- Increase (from the baseline year) the percentage rate of earnings gained by employed adult TANF recipients/former recipients between a base quarter and the second subsequent quarter.
- Increase (from the baseline year) in the number of children in a state living in married couple households as a percentage of all children in the state living in households.
- All States meet the TANF all-families work participation rate of 50% (including the caseload reduction credit).

Assets for Independence—HHS

The program supports grantees that encourage low-income families to save earnings in Individual Development Accounts (IDAs). IDAs are matched savings accounts that help low-income and low-wealth families accumulate savings for investments in long-term economic assets such as a house, higher education or a small business.

- Increase in the annual amount of AFI IDA savings (earned income only) participants use for the three asset purchase goals.
- Increase in the number of participants who withdraw funds for the three asset purchase goals.

Other

Developmental Disabilities Grant Programs

This program gives grants to help individuals with developmental disabilities and their families in accessing services and other assistance. These funds are designed to promote independence, productivity, and inclusion of those with developmental disabilities.

- By the end of FY 2007, the percentage of individuals with developmental disabilities who are independent, self-sufficient and integrated into the community, as a result of State Council efforts, will increase to 14 percent (SCDD).
- By the end of FY 2007, the percentage of trained individuals who are actively working to improve access of individuals with developmental disabilities to services and supports will increase to 94 percent.
- By the end of FY 2007, percentage of individuals who have their complaint of abuse, neglect, discrimination or other human or civil rights corrected will increase from 87% to 93% (P&As).
- Percentage of individuals who have their complaint of abuse, neglect, discrimination or other human or civil rights corrected compared to total assisted (P&A).

Independent Living for People with Disabilities

The Independent Living programs, which include the Center for Independent Living and IL State Grants programs, help individuals with disabilities live independently in their communities by providing skills training, counseling, information and referral, and assistance with individual and systems advocacy.

- As a result of direct services provided by a Center for Independent Living (including referral to another service provider), the percentage of CIL consumers who report having access to previously unavailable transportation, appropriate health care services, and/or assistive technology resulting in increased independence.
- The percentage of Centers for Independent Living staff, board members, and/or consumers participating in advocacy initiatives, such as community committees, public information campaigns, and other community events designed to increase the accessibility of transportation, health care, assistive technology, and affordable housing within their communities.

Assistive Technology Alternative Financing Program

The program awards Federal matching funds to encourage States to provide loans to individuals with disabilities to purchase assistive technology devices and services. This program makes assistive technology devices and services more available and accessible to individuals with disabilities and their families.

- There are no long-term measures currently but a web-based outcomes reporting system is being developed through the AFP technical assistance grant. This system will collect information to address the program's purpose, including data on how AFP loans have helped transform the lives of people with disabilities in employment, education and independent living.

Protection and Advocacy for Individuals with Mental Illness

Protection and Advocacy for Individuals with Mental Illness protects individuals with mental illness from abuse, neglect, and violations of their civil rights. The program

provides grants to independent protection and advocacy agencies which investigate and use legal and other remedies to correct verified incidents.

- Percentage of interventions on behalf of groups of PAIMI-eligible individuals that were concluded successfully.
- Increased percentage of complaints of alleged abuse and neglect, substantiated and not withdrawn by the client, that resulted in positive change for the client in her/his environment, community, or facility, as a result of PAIMI involvement.
- Increased percentage of complaints of alleged rights violations, substantiated and not withdrawn by client, that resulted in positive change through the restoration of client rights, expansion or maintenance of personal decision-making, or elimination of other barriers to personal decision-making, as a result of PAIMI involvement.

Food Stamp Program

The Food Stamp Program alleviates hunger and malnutrition among low-income individuals by providing eligible households coupons or electronic benefits redeemable for food at retail stores. It also supports State-administered nutrition education and employment and training assistance for food stamp recipients.

- Percent of eligible individuals who participate in food stamps.

Federal Transit Administration—Formula Grant Programs

The Federal Transit Administration's Urbanized Area and Fixed Guideway Modernization Formula Grant programs provide funding to help local transit agencies maintain and improve the condition of federally funded transit infrastructure. Eligible expenditures include buses, rail cars and rail systems.

- Ridership—Average percent change in transit boardings per transit market (150 largest transit agencies), adjusted for changes in employment levels. The ridership target was revised FY 2005 to 1.0 percent, based on the results of two years of data (FY 2003 and FY 2004) with the new measure.

- Accessibility—Increase the percentage of bus fleet that are ADA compliant (lift-equipped, ramp-equipped, or low floor).
- Accessibility—Increase the percentage of key rail stations that are ADA compliant.
- Condition—Stabilize and improve the condition of bus and rail fleet.

Appendix G: National Core Indicators

The National Core Indicators project is a collaboration among participating state agency members of the National Association of State Directors of Developmental Disability Services (NASDDDS) and the Human Services Research Institute (HSRI). The aim of the initiative is to identify and rigorously test performance and outcome indicators that will assist state developmental disabilities authorities in benchmarking their service system's performance against results being achieved elsewhere. The National Core Indicators also enables each participating state developmental disabilities agency to track system performance and outcomes from year to year on a consistent basis. Participation is voluntary and currently 23 states and 2 sub-state developmental disability agencies are using the indicators (<http://www.hsri.org/nci>).

This appendix provides a full list of outcome measures used in the National Core Indicators as an example of a program evaluation that integrates quality of life processes and outcomes into its measurement system.

The current set of performance indicators includes approximately 100 consumer, family, systemic, cost, and health and safety outcomes. Sources of information include consumer surveys (e.g., empowerment and choice issues), family surveys (e.g., satisfaction with supports), provider surveys (e.g., staff turnover), and state systems data (e.g., expenditures, mortality, etc.).

The core indicators include both objective and subjective measures; they are measurable and understandable. In addition, the indicators seem to be sensitive enough to identify differences among states because results are based on the consumer survey administered to 7,576 people residing in one of 15 states and one sub-state area in 2004–2005. Despite the relatively small sample sizes in some states (the sample sizes ranged from 224 in Delaware to 1,340 in Pennsylvania), states that were significantly better or worse than average could be identified with a high degree of statistical certainty.

As shown in Exhibit G.1, the consumer survey covers many of the domains and dimensions that were identified by our focus groups.

Exhibit G.1: NASDDDS Core Indicators Consumer Survey 2004/05

- Q1 Do you like working at [your job or day activity]?
- Q2 Is [staff who helps you at job/day activity] nice and polite to you?
- Q3 Do you like your home or where you live?
- Q4 Can you be alone if you want to?
- Q5 Are you ever afraid or scared when you are at home?
- Q6 Are you ever afraid or scared when you are out in your neighborhood?
- Q7 Is [staff who helps you at home] nice and polite to you?
- Q8 Do people (including staff) let you know before they come into your home?
- Q9 Do people (including staff) ask permission before coming into your bedroom?
- Q10 Do you have a best friend, or someone you are really close to?
- Q11 Do you have friends you like to talk to or do things with?
- Q12 Can you see your friends when you want to see them?
- Q13 Do you ever feel lonely?
- Q14 Can you see your family when you want to?
- Q15 Do you know your case manager/service coordinator?
- Q16 If you ask for something, does [your case manager/service coordinator] help you get what you need?
- Q17 Does [your case manager/service coordinator] ask you what you want?
- Q18 Do you know who your advocate or guardian is?
- Q19 Do people help you do new things you want to do?
- Q20 Do you want [more] help to do or learn new things?
- Q21 Are you happy with your personal life, or do you feel unhappy?

(continued)

Exhibit G.1: NASDDDS Core Indicators Consumer Survey 2004/05 (cont.)

- Q22 When you want to go somewhere, do you always have a way to get there?
- Q28 Do you go shopping?
- Q29 Do you go out on errands or appointments?
- Q30 Do you go out for entertainment?
- Q31 Do you always eat at home, or do you sometimes go out to eat?
- Q32 Do you go to religious services?
- Q33 Do you go to clubs or other community meetings?
- Q34 Do you exercise or play sports?
- Q35 Who chose the place where you live?
- Q36 How many places did you visit before moving here?
- Q37 Did you choose the people you live with (or to live by yourself)?
- Q38 Do you choose who helps you at home?
- Q39 Who decides your daily schedule?
- Q40 Who decides how you spend your free time?
- Q41 Who chose the place where you work (or go during the day)?
- Q42 How many places did you visit before working [at your job or day activity]?
- Q43 Do you choose who helps you at work?
- Q44 Do you choose what you buy with your spending money?
- Q45 Did you choose your case manager/service coordinator?
- Q46 Do people read your mail without your permission?
- Q47 Can you be alone with [guests], or does someone have to be with you?
- Q48 Are you allowed to use the phone when you want to?
- Q49 Have you ever participated in a self-advocacy group, meeting, conference, or event?
- Q50 Do you get the services you need?

Source: HSRI, NASDDDS 2006

Generally the indicators are each based on one question. There are several exceptions. For example, the proportion of people who participate in everyday integrated activities in their communities is calculated using Questions 28 to 32. The statistical methodology used to develop the scale is described in *Consumer Outcomes Phase VII Final Report Fiscal Year 2004–2005 Data* (HSRI, NASDDS 2006).

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