#### DRAFT MEMORANDUM

**SUBJECT:** Section 4302 of the Patient Protection and Affordable Care Act

(ACA): Disability-related data collection

FROM: Disability Rights Education and Defense Fund (DREDF)

DATE: April 2011

Section 4302 of the ACA mandates the collection of data on "disability status for applicants, recipients, or participants" by "any federally conducted or supported health care or public health program, activity or survey." In addition, section 4302 also requires the collection of additional information related to specific, known barriers to healthcare that affect individuals with disabilities and that contribute to the health and health care disparities they experience, and sets forth the following specific data collection standards:

"[S]urvey health care providers and establish other procedures in order to assess access to care and treatment for individuals with disabilities and to identify—

- "(i) locations where individuals with disabilities access primary, acute (including intensive), and long- term care;
- "(ii) the number of providers with accessible facilities and equipment to meet the needs of the individuals with disabilities, including medical diagnostic equipment that meets the minimum technical criteria
- "(iii) the number of employees of health care providers trained in disability and patient care of individuals with disabilities."

#### Problem

Disability is not simply the impact of impairment on, or its implications for, the individual, but also results from the interaction between an individual's impairment and the social, economic, and built environment. This current understanding of disability recognizes the impact of prejudice, discrimination, inaccessible architectural surroundings, and lack of accommodations such as Sign Language interpreters and accessible medical examination and diagnostic equipment. It replaces the long-held belief that disability equates inevitably with biologic dysfunction, disease and poor health.

In its *International Classification of Functioning, Disability and Health (ICF)*, the World Health Organization (WHO) recognizes that factors outside the individual contribute to the experience of disability. The ICF calls disability an "umbrella term for impairments, activity limitations or participation restrictions," conceiving "a person's functioning and disability... as a dynamic interaction between health conditions (diseases, disorders, injuries, traumas, etc.) and contextual factors" including environmental and personal

attributes. The ICF aims to shift the disability paradigm to universality, encompassing everyone:

Heretofore, disability has been construed as an all or none phenomenon: a distinct category to which an individual either belonged or not. The ICF, on the other hand, presents disability as a continuum, relevant to the lives of all people to different degrees and at different times in their lives.

Disability is not something that happens only to a minority of humanity, it is a common (indeed natural) feature of the human condition.... <sup>ii</sup>

Reflecting the new understanding of disability, the 1990 Americans with Disabilities Act<sup>iii</sup> and Section 504 of the 1973 Rehabilitation Act <sup>iv</sup> require that covered entities, including health care programs and facilities, remove physical barriers and provide needed accommodations and equipment, as well as prohibit disability discrimination in order to ensure equality of opportunity to participate in and benefit from care and services.

Disability rights laws such as the ADA, along with evolving public health research methods and the nomenclature of the ICF, have provided the foundation for a growing body of research on the type and prevalence of health disparities among people with disabilities when compared with the general population. For example, the Surgeon General of the United States, the Institute of Medicine (IOM), the National Council on Disability (NCD), the Centers for Disease Control and Prevention (CDC), the Agency for Healthcare Research and Quality (AHRQ), the National Institute for Disability Rehabilitation Research (NIDRR), and certain agencies of the National Institutes of Health have supported research and released seminal reports documenting what is currently known about access to health care and health disparities among people with disabilities. Moreover, Healthy People 2010, an initiative of the US Department of Health and Human Services, for the first time called for promoting the health of people with disabilities, preventing secondary conditions and eliminating disparities between people with and without disabilities in the US population. vi In spite of this progress, little data is available about key factors that affect access to health care and health care outcomes for people with disabilities.

The ACA, for the first time in federal law, acknowledged both the prevalence of health disparities among people with disabilities and that health disparities are not the inevitable outcome of disability or disease, but are the result of complex factors including lack of disability awareness on the part of health care providers, and architectural and programmatic barriers to care. Thus, the ACA calls for identifying disability status through population surveys and among applicants, recipients, or participants in federally conducted or supported health care or public health programs. Moreover, the ACA also calls for data to be collected that will reveal where people with disabilities obtain health care, the availability of accessible facilities and equipment, and the extent to which providers have received training on disability awareness and competency.

The ACA acknowledges disability status as a bona fide demographic characteristic. Moreover, there is a substantial body of work that addresses the identification in surveys of people with disabilities. However, survey methods thus far have not adequately revealed healthcare quality and the healthcare experience of those identified as having disabilities, nor have they pinpointed the barriers to healthcare for people with disabilities. The following discussion of national population surveys and recommendations is presented against this backdrop.

There are a number of national population surveys conducted or supported by the federal government that collect data on disability status and on health services use and expenditures. These include the National Health Interview Survey (NHIS), Medical Expenditures Panel Survey (MEPS), National Health and Nutrition Examination Survey (NHANES), the Survey of Income and Program Participation (SIPP), and the Behavioral Risk Factor Surveillance Survey (BRFSS) (see Table). Although not a population-based survey, the Medicare Current Beneficiary Survey (MCBS) also collects extensive information on the disability status and healthcare experiences of Medicare recipients. The American Community Survey (ACS) and Current Population Survey (CPS) also ask questions that identify who have a disability; however, they do not collect detailed information on health services use, expenditures, or experience. All the surveys with an explicit health information focus use the patient as the unit of analysis and, with the exception of the BRFSS, ask six or more questions about functional or activity limitation to identify respondents with disabilities. The BRFSS asks two questions that are not as well validated as the measures used in other surveys. The MEPS (which is a sub-sample of NHIS respondents), NHANES, and the MCBS also collect information about the services received that includes location of care and type of provider.

For many years, the federal health-focused surveys have included questions that allow the identification of disability using a set of questions based either on activity limitation or functional limitation. With a few important exceptions, vii the standard reporting of data from the surveys has often not reported out health services use or health outcomes and disparities by disability status. Analyses of the current data collection efforts have concluded that more, better, and *consistent* data are needed; however, there exists a base upon which to build a data collection strategy.

#### Federal Surveys with Disability Status and Health Services Characteristics Data

			Health & healthcare
Survey	Agency	Disability measures	measures
National	National	Activity limitation	• Cancer screenings (breast,
Health	Center for	<ul> <li>Activities of daily living</li> </ul>	cervical, colon)
Interview	Health	(ADL) & Instrumental	<ul> <li>Immunization and health</li> </ul>
Survey:	Statistics	Activities of Daily Living	behaviors (smoking,
NHIS	(NCHS)	(IADL)	drinking, obesity)
		<ul> <li>Mobility impairment scale</li> </ul>	<ul> <li>Delayed or missed</li> </ul>
		<ul> <li>Cognitive impairment</li> </ul>	healthcare due to cost
		<ul> <li>Deafness, hard of hearing</li> </ul>	<ul> <li>Didn't get needed mental</li> </ul>

Medical Expenditure Panel Survey: MEPS	Agency for Healthcare Research & Quality (AHRQ)	<ul> <li>Blindness, low vision</li> <li>Mental health disability</li> <li>Activity limitation</li> <li>ADL/ IADL limitation</li> <li>Mobility impairment scale</li> <li>Cognitive impairment</li> <li>Blindness, low vision</li> <li>Deafness, hard of hearing</li> </ul>	<ul> <li>healthcare/cost</li> <li>Usual source of care</li> <li>Additional questions on specific unmet needs or delayed care in sample adult &amp; child sections</li> <li>Cancer screenings (breast, cervical, colon)</li> <li>Delayed or missed healthcare or meds</li> <li>Usual source of care</li> <li>Provider characteristics</li> </ul>
Behavioral Risk Factor Surveillance System: BRFSS	Centers for Disease Control & Prevention	<ul><li> Use of Assistive Devices</li><li> Activity limitation</li></ul>	<ul> <li>Regular doctor</li> <li>Didn't get care because of cost</li> <li>Time since last checkup</li> </ul>
National Health And Nutrition Examination Survey: NHANES	National Center for Health Statistics (NCHS)	<ul> <li>Activity limitation</li> <li>ADL/ IADL limitation</li> <li>Mobility impairment scale</li> <li>Cognitive impairment</li> </ul>	Usual source of care
Survey of Income and Program Participation: SIPP	Census Bureau	<ul> <li>Activity limitation</li> <li>ADL/IADL limitation</li> <li>Mobility aids</li> <li>Mental health disability</li> <li>Vision and hearing impairments</li> <li>Speech difficulties</li> </ul>	<ul> <li>Hospital stays, doctor visits</li> <li>Usual source of care</li> <li>Home health care</li> </ul>
Medicare Current Beneficiary Survey: MCBS	Centers for Medicare and Medicaid Services (CMS)	<ul> <li>Visual &amp; hearing impairment</li> <li>Mobility impairment scale</li> <li>ADL/IADL</li> <li>Cognitive limitation</li> </ul>	<ul> <li>Cancer and other screenings</li> <li>Difficulty obtaining healthcare</li> <li>Delayed healthcare due to cost</li> <li>Usual source of care</li> <li>Reasons for changing/not having provider</li> <li>Provider quality</li> <li>Healthcare satisfaction</li> <li>Reasons for not seeking care</li> <li>Unmet need for medication</li> </ul>

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#### Recommendations

### Standardize questions about functional limitations using ACS questions as a starting point.

Six questions asking about functional limitations have now been incorporated into the ACS following cognitive testing and non-response assessment. These six questions are used to identify respondents with disabilities in the ACS and several other federal surveys. Thus, there is increasing consistency in the use of a set of questions to identify the population of persons with disability. The six questions in the American Community Survey (2008 version and subsequent) are:<sup>viii</sup>

- 1) Is this person deaf or does he/she have serious difficulty hearing? (17a: Hearing Disability, asked of all ages)
- 2) Is this person or does he/she have serious difficulty seeing even when wearing glasses? (17b: Visual Disability, asked of all ages):
- 3) Because of a physical, mental, or emotional condition, does this person have serious difficulty concentrating, remembering, or making decisions? (18a: Cognitive Disability, asked of persons ages 5 or older)
- 4) Does this person have serious difficulty walking or climbing stairs? (18b: Ambulatory Disability, asked of persons ages 5 or older)
- 5) Does this person have difficulty dressing or bathing? (18c: Self-Care Disability, asked of persons ages 5 or older)
- 6) Because of a physical, mental, or emotional condition, does this person have difficulty doing errands alone such as visiting a doctor's office or shopping? (19: Independent Living Disability, asked of persons ages 15 or older)

### Ensure that standardized disability questions identify people with functional limitations associated with certain cognitive, emotional, or learning impairments.

We support the use of the ACS questions as a starting point, but they are insufficient because they fail to identify people with limitations associated with certain cognitive, emotional, or learning impairments. We strongly recommend that additional questions that ask about these functions be added to the standard 6 for use in identifying disability status. These questions will need to be developed, but they can be built upon the experience with such questions in the health surveys. These additional questions are necessary because otherwise persons who experience health disparities and healthcare access barriers associated with their functional limitations are likely to be missed.

Collect activity limitation information at enrollment and point of care (in the electronic health record) and information about accommodations a patient needs to access services and to improve the quality of care.

The same activity limitation questions (the six-plus) should be used by health plans at enrollment. While the wording in the illustration above is in the third person, the questions are already used in the other surveys to ask the individual directly. In other words, they are self-reports of functional limitation. Where needed, a proxy (e.g. a parent or adult child) has answered these questions. Beyond this broad measure, a way to identify persons with specific risks of barriers to health care and health services is needed. Both at enrollment and point of care, information about what a patient needs to enable access would meet the data collection requirements and at the same time prepare providers with information that can improve the quality of care.

It is important to recognize that identification of individuals with disabilities in health care settings is a dynamic process. People need to be able to identify multiple functional limitations for themselves, and there needs to be a means to update this over time. With the establishment of electronic medical records, it will be feasible to incorporate the functional limitation questions into the record, completed by the patient (or proxy) as a part of the assessment information routinely collected when patients appear for care. The inclusion of these questions in the record will enable the patient characteristics to be connected to provider characteristics and in this manner provide data on the location where patients with disabilities receive care.

Other possibilities include working with the Systematized Nomenclature of Medicine Clinical Terms (known as SNOMED CT®) to extract functional status information. This is something that is being worked on within NCHS. The Institute of Medicine in its 2007 report recommended that health care settings and providers adopt the nomenclature of the *International Classification of Functioning, Disability and Health*, which is being used internationally. While it has its detractors because the full ICF classification is cumbersome, there should be consideration of using it in U.S. settings because condition specific identifiers of disability appropriately related to ICF domains are being developed. Thus the complete classification would not have to be used. ix

# Explore with CMS the possibility of retrieving information on locations where people with disabilities receive care who are Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) beneficiaries.

There are no known sources of information on the locations where people with disabilities receive health care. However, approximately 20 million children, adults, and seniors<sup>x</sup> with disabilities rely on Medicaid or Medicare for health insurance. We recommend that the Department of Health and Human Services (HHS) explore with the Centers for Medicare and Medicaid Services (CMS) the potential to retrieve information from CMS databases on the locations where people with disabilities who receive Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) benefits receive care. As the payer for services, CMS may have access to information that could assist in meeting the requirements of Section 4302. CMS should also obtain such information from states that collect it in relation to Medicaid funding. If such information is not readily available, as a condition of Medicaid payments to states, or Medicaid or Medicare payments to health care providers, CMS should require that providers develop methods to acquire the information called for in Section 4302 and report that information annually.

## Require identification of the number of providers with accessible facilities and equipment, including medical diagnostic and treatment equipment, as a condition of federal approval of state Medicaid plans and Medicaid waivers.

Limited information is currently available about the extent to which health care facilities and equipment are accessible and meet the needs of individuals with disabilities. Researchers have found that it is difficult to obtain data from healthcare providers, thus it has been difficult to obtain a quantitative estimate of access barriers, and no federal survey of accessibility of health care facilities yet exists. A recent research review reveals only a few studies that have collected information about healthcare provider accessibility. The studies involved small numbers of providers ranging from 10 to 68, with the exception of the California study of 2389 sites using the methodology that California will now use statewide described below.xi In light of the fact that lack of physical accessibility and accessible diagnostic equipment is cited as a reason why certain people with disabilities experience problems obtaining healthcare, it is especially important that steps be taken to begin to systematically collect this information.

In November 2010, California obtained an 1115 Medicaid waiver from the US Centers for Medicare and Medicaid Services (CMS) that permits mandatory enrollment in a managed care health plan of Medicaid beneficiaries who are people with disabilities and seniors residing in specific counties. As a term and condition of the waiver, California must require that Medicaid Managed Care Health Plans conduct accessibility surveys of the primary care practitioners who participate in their service networks. Data collected by the plans using an 86-question survey will be entered into a database managed by the individual Plan and relevant information on accessibility of provider facilities and services provided to member beneficiaries as needed.xii

Prior to this mandate, five Plans voluntarily conducted accessibility surveys with their networks of primary care providers between 2006 and 2010 using a 55-question research instrument. Research conducted using the outcomes of the combined data from these plans revealed levels of accessibility for 2,389 primary care provider facilities. The survey also evaluated availability of height-adjustable examination tables and wheelchair accessible weight scales in these facilities. Analysis of the combined data revealed significant access deficiencies in restrooms and certain parking facilities. However, the most notable outcome was the absence of accessible equipment: only 8.4% had height-adjustable exam tables and 3.6% had accessible weight scales.<sup>xiii</sup>

California's requirement that accessibility data be collected for network providers in Medicaid Managed Care Plans offers a unique, yet tested model for other states to collect such information. CMS should require that, as a condition of approval of the state Medicaid plan or any Medicaid waiver that permits mandatory enrollment of Medicaid beneficiaries into managed care, that Medicaid Health Plans with which the states contract for service be required to conduct either the same or a similar survey with their provider networks. Plans should provide outcomes to their respective states and, in turn, states should be required to provide the data to CMS as a method to meet the accessibility data requirement of Section 4302 of the ACA.

Other than those relatively few cases where a managed care organization directly hires and employs health care providers, providers who work individually or within group practices are free to engage in any number of managed care as well as fee for service contracts. In many cases, the provider who contracts to take Medicaid patients for a managed care plan is the same provider who also takes Medicare patients and private fee-for-service patients. The accessibility information obtained by plans through network surveys should therefore be widely applicable to all provider and provider offices. Thus, information about provider accessibility and availability of accessible exam, diagnostic and treatment equipment can be extrapolated for patients who are not part of a Medicaid program.

Condition the receipt of federal funds for the Affordable Choices of Health Benefits Plans, the Medicare Shared Savings Program, and the Community-based Collaborative Care Networks mandated by the ACA on both assurance of accessibility for people with disabilities and on the regular reporting of data to meet requirements of Section 4302. The ACA contains several provisions that provide opportunities to collect data on provider facility and equipment accessibility. Several provisions, for example, encourage states and providers to form consortia and collaboratives to improve coordination, quality, and cost-efficiencies. HHS should condition the receipt of federal funds for these initiatives on both assurance of accessibility for people with disabilities and on the regular reporting of data to meet the requirements of Section 4302. States, plans, providers an others involved with these consortia should be required to make this information available to consumers, as well as to HHS.

ACA Title I, Subtitle D, Sec. 1311 - Affordable Choices of Health Benefits Plans, provides grants to states to establish American Health Benefit Exchanges to facilitate purchase of qualified health plans. The Secretary of HHS is required to establish criteria for certification of qualified health plans, which must include, among other things, assurances of sufficient choice of providers, and include in the networks, providers that serve predominantly low income, medically underserved individuals. The health exchanges must, among other things, maintain a toll-free hotline to respond for requests for assistance and maintain an Internet website where enrollees and prospective enrollees can obtain standardized information on the plans. People with disabilities can only be adequately served if health exchanges include information about provider facility and equipment accessibility, and making this information available to consumers should be required for certification as a qualified health plan.

ACA Title III, Subtitle A, Sec. 3022 Medicare Shared Savings Program, provides incentives for physicians, group practices, and hospitals to join together to form "Accountable Care Organizations." The forming of these groups is intended to enable providers to better coordinate patient care, improve quality, help prevent disease and illness and reduce unnecessary hospital admissions. The Secretary of HHS is to establish criteria for how these providers work together and establish quality performance standards ACOs must meet to be eligible for payments for shared savings. The ACOs must provide the Secretary with "such information regarding ACO professionals

participating in the ACO as the Secretary determines necessary to support the assignment of Medicare fee-for-service beneficiaries to an ACO ... and to evaluate the quality of care furnished by the ACO." The Secretary should require that ACOs provide information on their facility and equipment accessibility if the Secretary is to make appropriate assignment of Medicare beneficiaries with disabilities, and properly evaluate the quality of care provided to beneficiaries with disabilities.

ACA Title X, Subtitle C, Sec. 10333 - Community-Based Collaborative Care Networks authorizes the Secretary to award grants to support community-based collaborative care networks - a consortium of health care providers with a joint governance structure that provide comprehensive, coordinated and integrated health care for low income populations. In awarding these grants, the Secretary is required to give priority to networks that, among other things, have "the capability to provide the broadest range of services to low-income individuals." According to a recent report, "People with disabilities account for a larger share of those experiencing income poverty than people in any single minority or ethnic group (or, in fact, all minority ethnic and racial groups combined)..." Thus, grantees should be evaluated for their capability to provide services accessible to people with disabilities. Grant applications for these funds should be required to include information about facility and equipment accessibility.

#### Collect health care practitioner training data available through the University Centers for Excellence in Developmental Disabilities (UCEDDs) as a starting point.

According to the National Council on Disability, "The absence of professional training on disability competency issues for health care practitioners is one of the most significant barriers preventing people with disabilities from receiving appropriate and effective health care."xv Moreover, disability competency is generally not a requirement for medical practitioner licensing, educational institution accreditation, or medical education loan forgiveness. There is no standard definition of what it means to be trained in disability or patient care of individuals with disabilities.

Faculty members working with certain medical and other professional health educational institutions that have an interest in promoting disability literacy and competency have worked to embed such courses in the curricula of their institutions, but no organized, combined measurement exists of the number of students who participate.xvi Some physicians and others concerned with disability and health have created self-paced online trainings for medical practitioners while disability and health advocates in California have developed training for health plans so their master trainers can increase disability competency among staff working in primary care facilities. xvii Perhaps the most robust health care practitioner training currently available is provided through the University Centers for Excellence in Developmental Disabilities (UCEDDs) funded through the Developmental Disabilities Assistance and Bill of Rights Act. "The UCEDDs provide community services such as training or technical assistance to people with disabilities, their families, professional and paraprofessional service providers, students, and other community members, and may provide services, supports, and assistance through demonstration and model activities."xviii HHS should collect any training data that is available through the UCEDDs as a starting point for assessing health care provider

training and awareness.

## Identify performance standards and monitoring measures related to disability competency as a condition of receiving Federal financial assistance for health care and related services.

Each of the recommendations set forth above for collecting data about health care providers' accessibility should also be considered for building in questions about provider disability competency. HHS should identify performance standards and monitoring measures that must be included as a condition of receiving Federal financial assistance to ensure that states, health plans, managed care organizations, and health care providers who receive Federal health care funds under Medicaid, the State Children's Health Insurance Program (SCHIP), and other Federal programs that pay for health care for people with disabilities meet the minimum requirements of the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act, and that they demonstrate sufficient cultural competency to provide effective health care to people with disabilities.

## Mount a targeted research project to assess the availability, content, and quality of disability competency training being offered through professional healthcare education and training programs

In light of the lack of established methods to collect information on the number of health care practitioners who have received disability training, HHS should mount a targeted project to collect such information. One method would be to generate a request for proposals from qualified research organizations that have the capacity to identify and assess the extent and content of training being offered through the various domains previously identified. Methods for regularly collecting this information should be established within an appropriate agency such as AHRQ or HRSA.

## Include development of mechanisms for collecting and reporting information about healthcare provider cultural competency in serving people with disabilities under section 5307 of the ACA

Section 5307 of the Affordable Care Act<sup>xix</sup> authorizes the Secretary of HHS to enter into contracts or cooperative agreements to develop, evaluate, and disseminate research, demonstration projects, and model curricula for cultural competency, prevention, public health proficiency, reducing health disparities, and aptitude for working with individuals with disabilities training for use in health professions schools and continuing education programs. Any such project should include the development of mechanisms for collecting and reporting information about provider cultural competency in serving people with disabilities.

# Add a query about disability cultural competency training to the existing queries about staff training to state-mandated healthcare provider facility site reviews required for Medicaid funding.

Another method to collect information about the extent of practitioner disability cultural awareness training is to add a line or lines to the existing queries about staff training to the site facility review required by the California Department of Health Care Services of

Medicaid Managed Care Health Plans. (Other states may have similar requirements.) The California full review already asks if there is evidence that staff have received training in a number of areas (e.g., infection control/universal precautions, informed consent, and child/elder/domestic abuse). Asking about evidence of training for disability awareness and patient care of individuals with disabilities could be an added inquiry.

#### Require Federally Qualify Health Centers (FQHCs) to collect data on disability and functional status.

Federally Qualified Health Centers (FQHC) should be required to engage in the data collection and provider site reviews described above as a condition of their federal funding. This should include the collection and federal reporting of data on provider staff training in disability awareness and patient care of individuals with disabilities. FQHCs also should be required to report on and provide the public with information about the availability of accessible facilities and medical equipment. Information collected about patients should indicate not only their functional limitations, but the kinds of accommodations they require and have been provided in the course of receiving health services.

HRSA and HHS should assist the FQHCs by providing basic training about use of a standardized survey that evaluates physical access as well as medical, diagnostic and treatment equipment accessibility (see above). Such training could either be arranged through contract with qualified community organizations, provided by regional HHS offices or through some other effective means.

<sup>v</sup> Publications include: "The Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities."

 $\underline{www.surgeongeneral.gov/library/disabilities/call to action/forward.html.}$ 

Institute of Medicine (IOM), *The Future of Disability in America* (Washington, DC: National Academies Press, 2007)

National Council on Disability (2009). The Current State of Health Care for People with Disabilities <a href="http://www.ncd.gov/newsroom/publications/2009/HealthCare/HealthCare.html">http://www.ncd.gov/newsroom/publications/2009/HealthCare/HealthCare.html</a> Centers for Disease Control and Prevention, Disability and Health Branch, "Healthy People 2010 Objectives for People with Disabilities."

http://www.healthypeople.gov/2020/topicsobjectives2020/pdfs/Disability.pdf.

<sup>&</sup>lt;sup>1</sup> J. Panko Reis, M. L. Breslin, L. I. Iezzoni, and K. Kirscher, *It Takes More Than Ramps to Solve the Healthcare Crisis for People with Disabilities* (Chicago: Rehabilitation Institute of Chicago, 2004)

<sup>&</sup>lt;sup>ii</sup> T. B. Ustun, N. K. Kostansjek, and J. Bickenback. "WHO's ICF and Functional Status Information in Health Records." Health Care Financing Review 24, no. 3 (2003): 82.

iii 42 U.S.C. §§ 12101 et seq.

iv 29 U.S.C. § 794

vi Healthy People 2010, Objectives for Improving Health, Disability, and Secondary Conditions. www.healthypeople.gov/Document/HTML/Volume1/06Disability.htm# Toc486927298

vii US Department of Health and Human Services, Agency for Healthcare Research and Quality, 2008 National Healthcare Quality and Disparities Reports, No. 09-0001, March 2009 http://www.ahrq.gov/qual/nhqr08/nhqr08.pdf

viii For additional information about these questions, see http://www.census.gov/hhes/www/disability/2008ACS disability.pdf.

- ix Stucki, G. & Melvin, J. 2007. The International Classification of Functioning, Disability and Health: A unifying model for the conceptual description of physical and rehabilitation medicine, *Journal of Rehabilitation Medicine*, 39: 286-292.
- Weigl, M., Cieza, A., Harder, M., Geyh, S., Amann, E., Kostanjsek, N., & Stucki, G. 2003. Linking osteoarthritis-specific health-status measures to the International Classification of functioning, Disability and Health (ICF), OsteoArthritis and Cartilage, 11: 519-523.
- \* Bob Williams and Henry Claypool. *Navigating Medicare and Medicaid, 2005: A resource guide for people with disabilities, their families, and their advocates.* Kaiser Family Foundation (2005). <a href="http://www.kff.org/medicare/upload/Navigating-Medicare-and-Medicaid-2005-A-Resource-Guide-for-People-with-Disabilities-Their-Families-and-Their-Advocates-Report.pdf">http://www.kff.org/medicare/upload/Navigating-Medicare-and-Medicaid-2005-A-Resource-Guide-for-People-with-Disabilities-Their-Families-and-Their-Advocates-Report.pdf</a>.
- xi Mudrick, N.R.; Breslin, M.L.; Yee, S.; and Liang, M. (2010). *Accessibility of Primary Health Care Provider Settings for People with Disabilities: Information from Health Plan Audits* [Slides]. Presented at the annual meeting of the American Public Health Association, Denver, CO. November 8.
- xii State of California, Health and Human Services Agency, Department of Health Care Services, MMCD Policy Letter 10-016 to All Medi-Cal Managed Care Health Plans regarding Revised Facility Site Review Tool, Dec. 31, 2010
- xiii Mudrick, N.R.; Breslin, M.L.; Yee, S.; and Liang, M. (2010). *Accessibility of Primary Health Care Provider Settings for People with Disabilities: Information from Health Plan Audits* [Slides]. Presented at the annual meeting of the American Public Health Association, Denver, CO. November 8.
- xiv Shawn Fremsted. "Half in Ten: Why Taking Disability into Account is Essential to Reducing Income Poverty and Expanding Economic Inclusion." Center fort Economic and Policy Research.," Washington, DC. 2009. p. 3.
- xv National Council on Disability (2009). The Current State of Health Care for People with Disabilities <a href="http://www.ncd.gov/newsroom/publications/2009/HealthCare/HealthCare.html">http://www.ncd.gov/newsroom/publications/2009/HealthCare/HealthCare.html</a>. Ibid., p. 265
- xvii Examples include: Women with Disabilities Education Program, www.womenwithdisabilities.org The Women with Disabilities Education Program concept emanated from a special task force consisting of practicing physicians and other healthcare professionals who have a strong commitment to providing high-quality medical care for women with disabilities. Principals include Lisa Iezzoni, MD, Medical Director, Harvard Medical School, Carol J. Gill, PhD, Associate Professor, Department of Disability & Human Development, University of Illinois at Chicago, and Jennifer E. Potter, MD, Associate Professor of Medicine, Harvard Medical School. The Program pursues two parallel tracts: a web-based self-management curriculum for patients and a training curriculum for health professionals. When completed, each curriculum will address a wide range of topics, from how to build better patient-provider relationships to how to diagnosis and treat acute medical problems in women with disabilities. Topical Webinar Series on Disability and Health: Integrating Disability Awareness and Women's Reproductive Health by the Association of University Centers on Disabilities (AUCD). This webinar introduces participants to a newly-developed online resource devoted to promoting reproductive health care for women with disabilities. This interactive recorded program, "Reproductive Health Care for Women with Disabilities," was developed through a partnership between the American College of Obstetricians and Gynecologists and the Centers for Disease Control and Prevention, and is designed to be an easily navigable source of information to assist clinicians providing care to women with physical, developmental, and sensory disabilities. xviii National Council on Disability (2009), p. 120.

xix Title V, Subtitle D, Sec. 5307 Cultural Competency, Prevention, and Public Health and Individuals with Disabilities Training.