The Right to Health: Fundamental Concepts and The American Disability Experience

National Council on Disability 1331 F Street, NW, Suite 850 Washington, DC 20004 202-272-2004 Voice 202-272-2074 TTY 202-272-2022 Fax

Lex Frieden, Chairperson

Publication date: August 2, 2005

Foreword

The National Council on Disability is an independent federal agency with 15 members appointed by the President of the United States and confirmed by the U.S. Senate. The overall purpose of NCD is to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities regardless of the nature or significance of the disability and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society. This topic paper is part of a series of topic papers designed to provide brief background information on United States disability policy for use by the delegates in their deliberations on the United Nations Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities.

I. Introduction

Health and Disability

Human health relates to many aspects of life in an interdependent and causal way. For instance, poverty is often the cause of poor health and poor health often results in poverty.

Education and health have a similar nexus: illness or infirmity can inhibit one's ability to gain an education, and health among the uneducated is generally worse than among the educated.

Likewise, poor health is often the cause of disability and disability can contribute to poor health.

To be sure, many disabilities have the potential to create health problems, or, "secondary conditions," however, the association between disability and health is far more complicated than simply that.

While issues such as poverty and education have long been recognized as having an important *relationship* with health issues, disability historically has been viewed as being itself a health issue. This perspective has led to the sidelining of disability within the social and human rights policy structures, relegating it to the medical community where it is subject to a public health or epidemiological approach. Within this structure, disability typically has been addressed in the same way as a disease would be, the emphasis being on prevention, cure and symptom management.

Fortunately, with the shift away from the "medical model" of disability and toward a "social" or "rights-based model" has come a more holistic perspective on disability and a more accurate understanding of its role as a health determinant. Health and disability are simply not mutually exclusive. People can be disabled and completely healthy. The disability community has worked tirelessly to move disability out of the medical framework and redefine disabilities as functional limitations, occurring as a natural part of human diversity and requiring an adjustment

of the social, physical and legal environments to accommodate them. By focusing on the barriers to participation of people with disabilities in society and the effect of these barriers on employment and educational status, access to housing, leisure activities, etc. of people with disabilities, it has become clear that higher incidence of disease and overall poor health of people with disabilities is a result of a myriad of factors related more to society's response to disability than the disability itself. For instance, employment discrimination against people with disabilities lends itself to poverty which lends itself to poor nutrition and thus to poor health. Lack of accessible transportation can prevent people with disabilities from visiting health centers when they are ill. Inaccessible public health programs mean that people with disabilities often do not receive critical information about the importance of exercise, the dangers of smoking (often increased for people whose disability affects respiratory capacity) or how to protect themselves from diseases such as HIV/AIDS.

The Right to Health

The general concept of the right to health made its first appearance in article 25.1 of the Universal Declaration of Human Rights:ⁱ

Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.

The idea was then isolated and defined somewhat more precisely in article 12 of the International Covenant on Economic, Social and Cultural Rightsⁱⁱ, adopted in 1966:

The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.

This articulation remains the fundamental expression of the right to health in international law.

Equally as important as seeking to understand what the *right* to health entails is understanding what is meant by "health." The World Health Organization, in the Preamble to its Constitution, iii declares that

Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.

The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, political belief, economic or social condition. . . .

Governments have a responsibility for the health of their peoples which can be fulfilled only by the provision of adequate health and social measures.

The right to health, as a matter of international law, is a broad and complex concept, subject to interpretation, and interdependent with many other established rights. Interestingly, the modern human rights movement was born partly as a result of the health-related human rights abuses perpetrated under the Nazi regime, namely the acts of physicians who performed terrible medical experiments on human subjects and then defended their actions as necessary, among other things, for the advancement of public health. The right to be free from such abuse at the hands of the medical establishment, and the obligation of governments to protect people from such actions, is perhaps the most straightforward and uncontested element of human rights

as they relate to the subject of medicine and health. Beyond this, the topic is multi-faceted and widely debated among human rights scholars, governments and citizens alike.

Purpose of this Paper

The practical purpose of a convention is to articulate human rights in a way that they may guide and inform States in the development, implementation and assessment of national programs and policies that seek to promote them. As the Ad Hoc Committee works to further develop and refine Article 21 of the draft of the Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities, NCD offers the following examples of US policies and programs designed and implemented in an effort to ensure the right of people with disabilities to enjoy the highest attainable standard of health. It is not the intent to argue that the approaches adopted in the United States are the best or only way of ensuring access for people with disabilities, but instead to provide this information as a resource to those engaged in ultimately implementing the new convention.

There are many areas in which the US health system has failed, and continues to fail, people with disabilities. The private sector, market-driven approach to health care access in the United States, though it has certain advantages for many Americans, has fundamental challenges and many holes through which vulnerable populations continue to fall, despite public programs such as Medicare and Medicaid. However, within this admittedly flawed system, there are countless efforts underway to improve the health situation of people with disabilities and it is these efforts that will be the focus of this paper.

Additional Note: NCD is aware that there has been some debate regarding whether rehabilitation should be dealt with in a separate section from health in the convention, given that

the general term "rehabilitation" is understood to be a multi-dimensional process that includes vocational, educational, psycho-social and other elements in addition to those that are medical in nature. While this paper offers no endorsement of addressing health and rehabilitation together or separately in the treaty, for the purpose of this document the terms "health care" and "medical care" are understood to be inclusive of those rehabilitation measures that are medically focused. The final section of the document will then address the growing awareness of the need for overall health policy and public health strategies to encompass the full range of rehabilitation concepts within efforts to promote human health among people with disabilities.

II. Freedom of Choice, Personal Autonomy

The Universal Declaration of Human Rights begins with the statement that all people are "born free and equal in dignity and rights." Personal freedom and self-determination are the foundation of laws that govern free societies. These concepts also play an important role in codes of medical ethics, which have long held that patients have the right to make independent choices regarding their health care. The World Medical Association, Declaration of Lisbon on the Rights of the Patient assert the following:

- 3. Right to self-determination
- a. The patient has the right to self-determination, to make free decisions regarding himself/herself. The physician will inform the patient of the consequences of his/her decisions.
- b. A mentally competent adult patient* has the right to give or withhold consent to any diagnostic procedure or therapy. The patient has the right to the information necessary to make his/her decisions. The patient should understand clearly what is the purpose of any test or treatment, what the

results would imply, and what would be the implications of withholding consent.

c. The patient has the right to refuse to participate in research or the teaching of medicine. iv

The right to make choices about one's own life, health and body are of particular concern to people with disabilities. At the heart of the issue is the right not to be institutionalized in a medical facility on the basis of disability. Ensuring this right must include both a general prohibition against legally forced institutionalization against the person's will as well as measures to eliminate the practical coercion that occurs when people with disabilities have no other options to access health and rehabilitative care.

People with disabilities have the right to live in their communities, accessing medical services in appropriate settings on an equal basis with others. This certainly should not preclude people with disabilities from having to visit doctors' offices, hospitals or clinics to address their medical needs – just as others must do. However, some people with disabilities require continuing care that cannot be managed effectively in traditional outpatient settings, yet, at the same time, is not so intensive or specialized that institutionalization would be a reasonable solution. In these cases, in-home medical support becomes the option most likely to meet the medical needs without creating the unnecessary segregation and loss of freedom often experienced by people in long-term care facilities. In short, accessing medical care outside of an institutional setting should not be more difficult for people with disabilities than for everyone else and a lack of accessible outpatient options must not force people with disabilities to make the untenable choice between forgoing needed care or submitting to long-term inpatient care (hospitals, nursing homes, etc.).

It should be noted that in some countries, home health visits are a common feature of mainstream medical care, while for others, including the United States, this is a practice that has all but disappeared except in certain remote rural areas. Therefore, providing home-based services in the US constitutes a departure from the norm and could be considered a "reasonable accommodation." The United States healthcare system can draw many lessons from other countries regarding how to incorporate home-based care into medical practice – both from a practical standpoint and in terms of ensuring cost-effectiveness.

(*The thorny legal issues regarding how mental competence is determined will not be discussed in this paper. However, this is a matter of great concern to people with disabilities. The assumption of mental incompetence based on disability has been a central feature of human rights violations in health care of people with disabilities.)

The Olmstead Decision^v

The 1999 *Olmstead* decision is not a law developed in the traditional manner - that is, written and passed by the United States Congress and signed into law by the President. Rather, it is a decision, rendered by the United States Supreme Court, which is based on civil rights legislation called the Americans with Disabilities Act (ADA)^{vi}. (*See next section for more information on the ADA*.) Specifically, it clarifies that requiring people with disabilities to live in institutions in order to obtain services constitutes illegal discrimination under the ADA. The *Olmstead* decision requires public entities to administer their services, programs, and activities "in the most integrated setting appropriate to the needs of qualified individuals with disabilities." The practical objective of the *Olmstead* decision is to move people from institutional care into community settings where they can access both the social and medical supports needed to live independently and live in their own communities.

Executive Order 13217viii

In 2001, President George W. Bush issued an Executive Order implementing the mandate of the *Olmstead* decision. An Executive Order is a legally binding order issued by the President to federal agencies in the Executive Branch of the US government. The purpose of an Executive Order is to direct agencies in the implementation of laws and policies. As NCD explains in its 2003 publication *Reclaiming Institutionalized Lives*, Executive Order 13217 "committ(ed) the Administration to implement the integration mandate of the ADA as interpreted in *Olmstead*. The Executive Order required federal agencies to promote community living for persons with disabilities by providing coordinated technical assistance to states; identifying specific barriers in federal law, regulation, policy, and practice that impede community participation; and enforcing the rights of persons with disabilities." A key component of the President's strategy was the instruction given to the Secretary of the US Department of Health and Human Services to coordinate with the Departments of Education, Labor, Justice, Social Security and Housing and Urban Development in a government-wide effort to address all of the factors that commonly impede people with disabilities from living independently in their communities.

MiCASSA

The *Olmstead* decision and subsequent implementation initiatives have created fundamental changes in the approach to health care for people with disabilities, eliminating institutionalization as the automatic solution to addressing long-term needs. However, there is still much work to be done to integrate the principles of community-based care and personal choice across the spectrum of US programs. Perhaps the most important current proposal is the Medicaid Community Attendant Services and Supports Act (MiCASSA). Medicaid is the federally funded health program, established in 1965 under the Social Security Act, which is

available to low-income individuals and people with disabilities who are not privately insured and cannot afford health care. In a 2003 Statement on the MiCASSA proposal, NCD described this important initiative:

MiCASSA, introduced but not yet enacted in the last several Congresses and supported overwhelmingly by the disability rights movement, is important because it would end the institutional bias of Title XIX of the Social Security Act by allowing people eligible for services from nursing facilities or intermediate care facilities for people with intellectual disabilities the election to receive community-based attendant services and support. Services covered by MiCASSA would include assistance with activities of daily living, including personal care, household chores, shopping, managing finances, using the telephone, participating in community activities, supervision, and teaching community living skills.

MiCASSA would require services that are provided in the most integrated setting appropriate to the needs of the individual;

* based on functional need, rather than diagnosis or age;

- * in home or community settings, including school, work, recreation, or religious settings;
- * selected, managed, and controlled by the consumer of the services;
- * supplemented with backup and emergency attendant services;
- * furnished according to a service plan agreed to by the consumer; and
- * accompanied by voluntary training on selecting, managing, and dismissing attendants.*

MiCASSA has not yet been passed by Congress, although some elements in the proposal have been put into practice through administrative and community action. The United States disability community and many lawmakers are working hard to see this important legislative initiative become law.

Summary

Both the *Olmstead* decision and MiCASSA are based on the overarching philosophy that segregation from society via institutionalization is a direct threat to the health and well-being of people with disabilities and furthermore prevents people from reaching their potential to participate in, and contribute to, community life. Community integration of people with disabilities requires that the health services be made available to them either in traditional outpatient settings or in their homes.

The establishment of legal mandates is only the first step toward changing the system of care that has long favored provision of care in an institutional setting. There are many new funding initiatives to help states make the transition from institutional to community based care. Some of these are described in another paper in this series, "Living Independently and in the Community: Implementation Lessons from the United States."

II. Equality and Non-Discrimination in Health Care: Ensuring Access and Eliminating Disparities in Quality of Care

Not unrelated to questions of personal autonomy and choice are the issues of equality and non-discrimination. Philosophical questions regarding these important concepts persist across the spectrum of health care – and will continue to persist as long as health care remains a globally scarce resource. In many countries, the supply of personnel, facilities and medicines is only a fraction of what it needs to be in order to provide adequate medical care to the entire population. In some wealthier countries, technology has simply outgrown the capacity of the

system to provide (on a financial and/or practical level) the services made possible by new innovations. The common theme is that demand universally outweighs supply when it comes to health services. This is true in private systems as well as government-controlled systems.

Rationing of care is happening everywhere — whether through market forces or explicit prioritization policies - creating ethical and human rights dilemmas worldwide. Simply stated, in most if not all societies, there is an ongoing and agonizing debate regarding what constitutes adequate care for any given individual and what criteria should be used to determine it. This is no different when it comes to people with disabilities.

What is different, however, is the fact that health care services are often made more scarce for people with disabilities because they are designed and delivered in a way that fails to account for the access needs created by different disabilities. In other words, failure to provide reasonable accommodations in the health care setting often prevents people with disabilities from securing those services to which they are entitled within the resources available and according to the allocation mechanism in place. Inaccessible facilities and exam tools lead to incomplete care, or care of diminished quality, for people with disabilities. For instance, mammogram machines to screen for breast cancer are commonly inaccessible for women with mobility impairments. Another frequently forgotten area within the overall healthcare equation for people with disabilities is dental health. Dental offices are often inaccessible and equipment such as dentist chairs and x-ray machines do not accommodate many disabilities. Furthermore, even when the physical environment has been perfectly adapted and communications barriers accounted for, a lack of understanding of disability issues among health professionals can

minimize the effectiveness of the services they provide, xii creating yet another roadblock for people with disabilities in claiming their rights in the area of health care.

<u>Accessibility and Reasonable Accommodation in Health Care</u> <u>The Rehabilitation Act of 1973</u>^{xiii}

The Rehabilitation Act of 1973 prohibits discrimination on the basis of disability in all programs conducted by federal agencies or by organizations receiving federal financial assistance. Section 504 of the Rehabilitation Act specifically prohibits discrimination in "service availability, accessibility, delivery, employment, and the administrative activities and responsibilities of organizations receiving Federal financial assistance." This includes:

- denying qualified individuals the opportunity to participate in or benefit from federally funded programs, services, or other benefits.
- denying access to programs, services, benefits or opportunities to participate as a result of physical barriers.

NCD noted in its 2003 publication *Rehabilitating Section 504*: "As the largest grantmaking agency in the Federal Government, the U.S. Department of Health and Human Services (HHS) has had extraordinary power to enforce the nondiscrimination provisions of Section 504. When its programs were part of the Department of Health, Education and Welfare (HEW), HHS played the critical role of issuing the first Section 504 regulations, as well as model regulations for all other federal agencies. HEW was also lead agency for the enforcement of Section 504."xiv

The Americans with Disabilities Act (ADA)

The Rehabilitation Act was an important step toward ensuring non-discrimination for people with disabilities; however, it applies only to federal and federally funded entities. The ADA, enacted in 1990, is a far-reaching piece of legislation developed in an effort to entrench the principles of non-discrimination in a broad range of areas across American society. The anti-

discrimination protections provided by the ADA extend to health care providers both in the private and public sectors. Publicly funded health services and facilities are covered by Title II of the ADA, which applies to all programs, activities and services conducted by state and local governments. Private sector health services and facilities are covered by Title III, which covers "public accommodations," meaning entities that provide goods or services to the general public. Public accommodations include such things as restaurants, sports stadiums, shops, zoos, funeral homes and private hospitals and doctors' offices.^{xv}

In terms of physical access, all entities are subject to specific design and construction standards outlined in the *Americans with Disabilities Act Accessibility Guidelines (ADAAG)*. It should be noted that, in recognition of the importance of health services, higher standards of accessibility have been set for buildings in which health services are located. For instance, a new two-story office building that would otherwise not be required to install an elevator must do so if health care offices are to be located in that building. In the subject to specific design and construction standards of the standards of the services are located.

Equally as important as physical access to the health care environment is ensuring appropriate communications access, including, for example, the provision of sign language interpreters during consultations and physical exams, and alternative formats for health promotion information and other written products.

Implementation Initiatives

To facilitate the implementation of the principles of accessibility and reasonable accommodation in the health care environment, information and assessment resources and programs for health care providers have been developed. In addition to guidelines regarding physical accessibility, accessible communications and other measures required by law, many of these programs include a focus on quality assurance related to intangible factors such as

understanding disability issues beyond the health aspects, avoiding stereotyping and learning appropriate terminology and language to discuss disability.

The National Institute on Disability and Rehabilitation Research (NIDDR)

NIDRR, which is part of the Department of Education's Office of Special Education and Rehabilitative Services (OSERS), conducts "comprehensive and coordinated programs of research and related activities to maximize the full inclusion, social integration, employment and independent living of individuals of all ages with disabilities." Much of NIDRR's work is accomplished through partnerships with educational, scientific and advocacy groups in the form of Rehabilitation Engineering Research Centers (RERCs).

The RERC on Accessible Medical Instrumentation (AMI)^{xix} is of particular interest in this context because its work has a direct impact on accessibility in the health care setting. The cornerstone project of RERC-AMI is a comprehensive needs assessment program involving healthcare consumers, healthcare service providers, and medical device manufacturers. RERC-AMI also conducts policy analysis activities with health care providers, medical education institutions and public policymakers regarding "standards for design and procurement of medical instrumentation."^{xx}

One of the partner organizations of RERC-AMI is the Center for Disability Issues in the Health Profession (CDIHP). **XXI** Through RERC-AMI funding, CDIHP has developed **Tools For Decreasing Health Care Barriers: Accessible Health Care Briefs.**

This series of information resources is designed to educate health care administrators, healthcare workers and consumers alike. Subjects include, for example, *The Importance of Accessible Examination Tables*^{xxiii} which explains not only what features are required in order for a table to comply with ADA standards but also how such equipment can improve health

outcomes for people with disabilities. The series also includes a document entitled *Health Care*Facilities Access^{xxiv} which provides a comprehensive illustrated overview of how to ensure complete accessibility throughout the health care setting.

In addition to establishing RERCs, NIDRR provides funding to many private organizations involved in efforts to promote accessible health care for people with disabilities.

The Centers for Disease Control and Prevention (CDC)

Part of the US Department of Health and Human Services, CDC is known worldwide for its research and health promotion activities. CDC has established the "Disability and Health Team" as part of its National Center on Birth Defects and Developmental Disabilities. One of the stated goals of the Disability and Health Team is to "offer training to health professionals interested in the field of disability and pubic health." The Disability and Health Team conducts its own projects but also provides critical support to state health departments, universities, and national organizations to "develop state disability and health programs, implement interventions that promote the health of people with disabilities throughout their lifespan, deliver health communication messages, and assess the health status of people with disabilities."

One example of a CDC funded project is *Removing Barriers to Health Care: A Guide for Health Professionals*. XXVII Developed by the North Carolina Office on Disability and Health, this guide provides information not only about how to improve the physical environment, ensure equal access and comply with the ADA, but also information to help providers understand how to improve their "personal interactions with patients with disabilities." This guide seeks to help health providers take steps beyond the legal requirements to create comprehensive, consumeroriented strategies to improve the health care experience of people with disabilities. In 2004, more than 3,000 copies of this resource were disseminated throughout the country. XXVIII

CDC also funds many initiatives specifically directed at the special health care access needs of women with disabilities, including the development of a *Providers Guide for the Care of Women with Physical Disabilities and Chronic Medical Conditions*^{xxviii} and an important study aimed at improving access of women to breast cancer screening programs.^{xxix}

III. Public Health Strategies: Including People with Disabilities as part of a Healthy and Prosperous Nation

One of the most significant barriers for people with disabilities to enjoying good health is the failure to mainstream disability issues in public health programs and health promotion campaigns. People with disabilities are often disregarded in anti-tobacco campaigns, breast cancer awareness initiatives, HIV/AIDS prevention programs, education programs stressing the importance of exercise, etc. This disregard may be in the form of neglecting to ensure that the information is provided in an accessible format or it may be related to a false assumption that the information and strategies are appropriate for all people, regardless of disability. As a result, people with disabilities have been found to be at increased risk for smoking, xxx obesity, txxi and other preventable conditions.

The most far-reaching and in-depth public health program in the United States had its beginnings in 1979 when the US Surgeon General released its annual report, entitled "Healthy People," which laid the foundation for a national public health agenda. Healthy People 2000 was subsequently developed for implementation between 1990 and 2000. A comprehensive ten-year plan with specific objectives to be achieved during the decade, Healthy People 2000 was subject to extensive annual progress reviews throughout the course of its implementation. The success of Healthy People 2000 led to the current initiative, Healthy People 2010. The development and implementation of this plan involves numerous federal agencies and a

consortium of more than 400 national organizations, all State health departments, and key national associations of State health officials. xxxiii

The reviews stemming from the Healthy People 2000 included recommendations that a new focus area on disability be added to the next plan. (Although Healthy People 2000 included some objectives targeting people with disabilities, disability was not prioritized as a specific focus area within the overall agenda.) As a result of these recommendations, *Healthy People* 2010 includes an entire section dedicated to the health of people with disabilities. The stated goal of Healthy People 2010, Chapter 6: Disability and Secondary Conditions is to "Promote the health of people with disabilities, prevent secondary conditions, and eliminate disparities between people with and without disabilities in the U.S. population. xxxiv Using the World Health Organization's International Classification of Functioning and Disability and Health (ICIDH-2) xxxv as a "framework for describing functioning, health, and disability status among all people" this chapter includes thirteen specific objectives for promoting the health of people with disabilities and plans for achieving them. xxxvi (See endnote for full text of the thirteen objectives.) These goals encompass a broad array of concepts that go far beyond traditional public health notions of disease prevention or the historical approach to rehabilitation. They include the removal of environmental and social barriers that inhibit the full human development of people with disabilities. They advocate for education and vocational rehabilitation as critical factors to help people with disabilities reach their employment potential. They focus strongly on the debilitating secondary conditions of isolation and depression and promote permanencyplanning principles that will move people from institutions in to the community. In short, Healthy People 2010 takes a holistic approach to promoting the physical, mental, economic and social health of people with disabilities.

The importance of targeting people with disabilities in this critical national strategic plan cannot be underestimated. In his article entitled "Public Health and Disability: Emerging Opportunities" author Donald J. Lollar, EdD commented on the impact of including a disability focus in *Healthy People 2010*.

The Healthy People 2010 agenda has provided the impetus for alliances to improve the health of people with disabilities....The growing partnership among disability advocates, university researchers, and state and federal disability program staff members provides the core relationships from which creative and productive leadership for the future is emerging. xxxvii

IV. Conclusion

Assuring the "highest attainable standard of health" for people with disabilities depends largely on the available resources and the allocation mechanisms of each country's healthcare system. However, the core principles of fairness, equality, reasonable accommodation and accessibility should be the foundation upon which strategies, policies and programs are developed. The above examples from the US experience represent some of the best efforts of the American people to feature these principles centrally in our approach to health care for people with disabilities. It is hoped that the Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities will provide a moral and legal framework that supports the development of plans and systems that take these efforts to an even higher level worldwide. Indeed, the health of all people should be viewed as a precious public commodity, necessary for the prosperity, security and development of societies.

Acknowledgements

The National Council on Disability wishes to express its appreciation to Joelle Balfe, Consultant, for drafting this topic paper.

ⁱ Universal Declaration of Human Rights, Dec. 10, 1948, art 1, G.A. Res.v217 (III), at 71, UN Doc. A/810 (1948)

ii G.A. res. 2200A (XXI), 21 U.N. GAOR Supp. (No. 16) at 49, U.N. Doc. A/6316 (1966), entered into force Jan. 3,

iii Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19-22 June, 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 7 April 1948.

iv World Medical Association, Declaration of Lisbon on the Rights of the Patient, Adopted by the 34th World Medical Assembly Lisbon, Portugal, September/October 1981 and amended by the 47th General Assembly Bali, Indonesia, September 1995 (Available at www.wma.net)

^v 527 U.S. 581 (1999). Olmstead v. L.C

vi Americans with Disabilities Act, 42 U.S.C. § 12111(9) (1990).

vii Supra note v.

viii Exec. Order No. 13,217, 66 Fed. Reg. at 33,155 (2001).

ix National Council on Disability: Reclaiming Institutionalized Lives, 2003. Available at http://www.ncd.gov/newsroom/publications/2003/pdf/reclaimabridged.pdf

x Statement by the National Council on Disability on MiCASSA, NCD#03-427, February 14, 2003, available at www.ncd.gov/newsroom/news/2003/r03-487.htm.

xi Breast Health Access for Women with Disabilities (http://www.bhawd.org/sitefiles/index2.html)

xii Lisa I. Iezzoni, MD, MSc; Roger B. Davis, ScD; Jane Soukup, MSc; Bonnie O'Day, PhD. Quality Dimensions that Most Concern People with Physical and Sensory Disabilities. Arch Intern Med. 2003:1632085-2092 xiii Rehabilitation Act, 29 U.S.C. § 701 (1994).

xiv National Council on Disability: Rehabilitating Section 504, 2003, available at www.ncd.gov/newsroom/publications/2003/Section504.htm.

xv National Council on Disability and National Urban League: A Guide to Disability Rights Laws, June 27, 2002. (Available at www.ncd.gov/newsroom/publications/2000/pdf/disabilityrights.pdf)

xvi ADA Accessibility Guidelines for Buildings and Facilities (As amended through September 2002). (Available at www.access-board.gov/adaag/html/adaag.htm)

xvii Removing Barriers to Health Care A Guide for Health Professionals: Developed by the Center for Universal Design and the North Carolina Office on Disability and Health. (Available at www. fpg.unc.edu/%7Encodh/RBar/index.htm#list)

See NIDRR section of the Department of Education website at www.ed.gov/about/offices/list/osers/nidrr/about.html

xix See RERC-AMI website at www.rerc-ami.org/ami/

xxi See CDIHP website at www.cdihp.org.

xxii June Isaacson Kailes MSW; Christie Mac Donald MPP; Center for Disabilities and the Health Professions, Western University of Health Sciences "Tools for Decreasing Health Care Barriers: Accessible Health Care Briefs. Available at www.cdihp.org/products.html#access briefs. xxiii *Id*.

xxiv *Id*.

xxv See homepage for CDC/NCBDDD Disability and Health Team at www.cdc.gov/ncbddd/dh/default.htm

xxvi Removing Barriers to Health Care: A Guide for Health Professionals, produced by the Center for Universal Design and The North Carolina Office on Disability and Health. Available at www.fpg.unc.edu/%7Encodh/RBar/index.htm#list

xxvii Personal interview with Chrystal Smith, North Carolina Office on Disability and Health

xxviii Sandra Welner, MD, Providers Guide to for the Care of Women with Physical Disabilities & Chronic Medical Conditions, available at http://www.fpg.unc.edu/~ncodh/Providerhtml.html.

xxix For more information see www.cdc.gov/ncbddd/women/cancer.htm

xxx Disability and Health: Promoting the Health and Well-Being of People with Disabilities, 2004. Produced by CDC/NCBDD. Available at http://www.cdc.gov/ncbddd/factsheets/Disability Health AtAGlance.pdf

xxxi James H. Rimmer, PhD: The Conspicuous Absence of People with Disabilities in Public Fitness and Recreation Facilities: Lack of Interest or Lack of Access? Am J Health Promot 2005;19(5)327-239

xxxiii See Healthy People website, Implementation Section at www.healthypeople.gov/Implementation/

xxxiv Healthy People 2010, Chapter 6: Disability and Secondary Conditions, available at http://www.healthypeople.gov/Document/HTML/Volume1/06Disability.htm

xxxv World Health Organization (WHO). International Classification of Functioning and Disability (ICIDH-2): WHO/HSC/ACE/99.1

xxxvi The thirteen objectives outlined for people with disabilities in Health People 2010 are:

- Include in the core of all relevant Healthy People 2010 surveillance instruments a standardized set of questions that identify "people with disabilities".
- Reduce the proportion of children and adolescents with disabilities who are reported to be sad, unhappy or depressed.
- Reduce the proportion of adults with disabilities report feelings such as sadness, unhappiness or depression that prevent them from being active.
- 6-4 Increase the proportion of adults with disabilities who participate in social activities.
- 6-5 Increase the proportion of adults with disabilities reporting sufficient emotional support.
- 6-6 Increase the proportion of adults with disabilities reporting satisfaction with life.
- Reduce the number of people with disabilities in congregate care facilities, consistent with permanency planning principles.
- 6-8 Eliminate disparities in employment rates between working-aged adults with and without disabilities.
- 6-9 Increase the proportion of children and youth with disabilities who spend at least 80 percent of their time in regular education programs.
- 6-10 (Developmental) Increase the proportion of health and wellness and treatment programs and facilities that provide full access for people with disabilities.
- 6-11 (Developmental) Reduce the proportion of people with disabilities who report not having the assistive devices and technology needed.
- 6-12 (Developmental) Reduce the proportion of people with disabilities reporting environmental barriers to participation in home, school, work, or community activities.
- 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.

xxxvii Donald J. Lollar, EdD: Public Health and Disability: Emerging Opportunities. Public Health Reports / March-April 2002 / Volume 117

xxxii See Yale University/World Bank HIV/AIDS and Global Disability Study for more information. Available at cira.med.yale.edu/globalsurvey/index.html