

Access to Medical Care

Training Tools for Health Care Providers,
Disabled Patients and Advocates on
Culturally Competent Care and Compliance
with Disability Law

This training guide accompanies the two DVDs:

***Access to Medical Care: People with
Developmental Disabilities***

and

***Access to Medical Care: Adults with Physical
Disabilities***



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The World Institute on Disability (WID) is a nonprofit research and public policy center promoting the civil rights and full societal inclusion of people with disabilities. WID's work focuses on four areas: employment and asset development; accessible health care and personal assistance services; inclusive technology design; and international disability and development. As over half of the Board of Directors and staff are people with disabilities, WID brings a diverse disability perspective to improving public policy and civil rights.

A Training Curriculum on Improving Access and Quality of Care for Individuals with Disabilities

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Introduction

Social and political gains of the disability rights movement, culminating in the *Americans with Disabilities Act* of 1990, are changing how the medical system views people with disabilities. Medical professionals in all types of facilities must now understand disability as more than physical, cognitive, or emotional dysfunction. A new model, which takes into account the intersection of disability with other marginalized constituency factors, such as gender and race, must be envisioned.¹ This new model must address the full range of barriers, including environmental, architectural, logistical, societal, and cultural, that define and impact the health of disabled individuals as much as their biologic impairments.² Providers are becoming aware that appropriate care at the outset can help prevent unnecessary emergency-room visits, costly case mismanagement, and dangerous secondary conditions.

About 18%, or 51.2 million, individuals with disabilities reside in the United States.³ Of those, an estimated thirty million are women.⁴ Yet they must struggle to find health care providers who are sensitive to their needs. Many individuals with disabilities, particularly those who grew up with a disability or with severe impairments, may encounter patronizing attitudes and ignorance by health care practitioners, damaging their sense of independence and well-being, and reducing the quality of care they receive. Discrimination against disabled individuals restricts their employment, education, and participation in the community.

¹ U.S. Department of Education. Office of Special Education and Rehabilitation Services, National Institute on Disability and Rehabilitation Research. 2000. *Long Range Plan: 1999-2000, Executive Summary*. Washington, DC: GPO, 2000.

² Institute of Medicine. Committee to Review the Social Security Administration's Disability Decision Process Research. National Research Council. Committee on National Statistics. Wunderlich GS, Rice DP, Amado NL, eds. *The Dynamics of Disability. Measuring and Monitoring Disability for Social Security Programs*. Washington, DC: National Academy Press, 2002.

³ <http://www.realising-potential.org/stakeholder-factbox/disabled-people-worldwide/>

⁴ Fact Sheet: Women and Disability Rehabilitation International and the World Institute on Disability, July, 1997. <http://dawn.thot.net/fact.html>

Compared to non-disabled individuals, persons with disabilities are among the most frequent consumers of medical services. Yet not all of them require extra medical treatment. Rather, they have to visit their physicians because some non-medical services, such as Social Security benefits, wheelchair transportation, and personal assistance services, require “certification as disabled” by a medical doctor. However, physicians receive little training about the social issues that affect disabled individuals and their unique health circumstances.

A new disability paradigm has emerged from decades of research and advocacy growing out of the Disability Rights and Independent Living movements. Health care professionals will benefit from becoming more aware of the community resources that are available to disabled individuals and their families, including peer counseling, mutual support groups, independent living, advocacy, and recreational services. Expanding providers’ knowledge and improving communication between patients and providers are highly critical to delivering quality medical care to individuals with disabilities.

This curriculum and the accompanying videos, *Access to Medical Care: Adults with Physical Disabilities* and *Access to Medical Care: People with Developmental Disabilities*, offer practitioners, including physicians, dentists, and nurses, as well as social service and support staff, an introduction to crucial issues that affect the quality of care for patients with physical, sensory, and communication disabilities. This program offers a focus on physical disability, including mobility, vision, hearing, and communication impairments, and emphasizes access and communication as the fundamental components of quality care for individuals with disabilities.

The accompanying videos illuminate the perspectives of disabled individuals and expert providers, discussing the access and communication issues that often arise in the clinic setting, and the requirements of the *Americans with Disabilities Act* in addressing these issues. The curricular materials offer a case-based training exercise that challenges viewers to put knowledge into practice for nine patients with various disabilities. This exercise can be used immediately after viewing the videos, at subsequent training sessions, or for individual self-administration.

Also included in the curriculum is a list of top-rated searchable websites related to disability, links to downloadable resource guides about the *Americans with Disabilities Act*, and an extensive bibliography for further study on clinical and related research topics.

Training Goals

The overall goals for this training program are to improve the delivery of culturally sensitive quality medical care to individuals with physical, sensory, and communication disabilities and chronic illness, and compliance with the requirements of the *Americans with Disabilities Act*.

Participants will be able to

- gain a better understanding of health, wellness, and care issues for individuals with physical, sensory, and communication disabilities;
- recognize crucial issues which affect access to quality health care, including architectural, communication, attitudinal, and economic policy barriers, as addressed in the *Americans with Disabilities Act*;
- acquire specific skills to promote good communication and rapport between providers and patients, which in turn enhance accurate assessment and delivery of quality medical care.

Components of the Training Package

The training curriculum guide includes the following parts:

- Suggestions for Teachers and Trainers about disability issues relevant to disabled individuals
- Workshop Facilitator's Guide
- Two Videos
 - a) *Access to Medical Care: Adults with Physical Disabilities*
 - b) *Access to Medical Care: People with Developmental Disabilities*
- Fact Sheet: Medical Care and Disability Awareness
- Four Workshop Handouts
 - a) Definition of a Person with a Disability under the *Americans with Disabilities Act*
 - b) Barriers to Health Care
 - c) How to Provide Quality Medical Care to Individuals with Disabilities
 - d) Stimulus Questions: Applying Access Information and Rapport Skills
- Case Examples for Discussion as part of small-group exercises or for individual study

- Additional Case Considerations for further discussion of the Case Examples
- Tips for Individuals with Disabilities on Expecting and Receiving Quality Medical Care
- Evaluation Form
- Downloadable Comprehensive Guides and E-Courses on Disability Issues, Cultural Competence and the *Americans with Disabilities Act*. Each guide has extensive references for further study. The downloadable guides include strategies for
 - ❖ communication with disabled people
 - ❖ planning for programmatic access and accommodation
 - ❖ architectural access issues
 - ❖ medical education
 - ❖ consumer/ patient perspectives
 - ❖ Medicaid policy barriers and issues
- Annotated Online Resource Guide for Providers Serving People with Disabilities featuring searchable disability-related websites, for use in treatment management, referral, and consumer information
- Bibliography of Pertinent Articles and Books on Disability Issues and Research

Suggestions for Teachers and Trainers about Disability Issues

Training medical providers about disability requires sensitivity and knowledge of a range of complex social, personal, medical, political, and legal issues. This section offers suggestions for teachers and trainers to optimize the quality of the training workshop experience for participants.

Recommended Qualifications of Trainers

It is recommended that at least one of the trainers, but preferably all of the workshop facilitators have the following key qualifications:

- Sufficient experience with personal, social, and cultural issues affecting people with disabilities to be able to answer common questions about disability access, legal, and social issues, and to challenge common stereotypes about people with disabilities;
- Thorough knowledge of Title III of the *Americans with Disabilities Act* (ADA), which covers places of public accommodations;
- Working knowledge of community and academic literature related to disability;
- Direct personal experience with disability issues, such as having a disability or being a parent, primary caregiver, offspring, sibling, spouse, or common-law partner of a person with a disability.

These qualifications are designed to enlist knowledgeable trainers who have a "disability positive view," as well as technical knowledge essential to the content of this program. In some settings, service professionals may be the most appropriate facilitators. It is essential to remember that the most fundamental challenge to disability stereotyping comes from participants interacting with people with disabilities in a peer or leadership role. Non-disabled medical professionals can involve at least one co-trainer who is a person with a disability and who possesses the above qualifications. A recommended training format is included in this packet. Additional training suggestions are below.

Panel Presentations

A panel presentation by individuals with disabilities is an excellent way to offer exposure to personal experiences and points of view about disability within a manageable time frame. Panel members can be chosen on the basis of their ability to effectively communicate their own experiences. In considering candidates, it is important not to exclude people because of limited education, class background, communication disabilities, or stereotyped notions of "presentability." Diversity of disability, level of education, and race will greatly enhance the impact and applicability of the panel presentation.

Panel members can be instructed to develop a brief presentation of approximately five to ten minutes, in which they share personal stories of their life and medical experiences, which should illustrate points consistent with the objectives of the training. Inexperienced panel members may need assistance with the process of framing their stories concisely. Individuals interviewed in the video *Access to Medical Care: Adults with Physical Disabilities* model clear, assertive, and positive suggestions to providers.

Personal stories of negative or discriminatory experiences can be most effective when conveyed with (1) an attitude that discriminatory treatment is the result of lacking information and appropriate exposure to and positive interaction with people with disabilities; and (2) the positive expectation that discriminatory treatment can be reversed with training, experience, and knowledge of appropriate legal, ethical, and social guidelines. The above points can be stated directly by the trainer in private coaching sessions with panel members, as well as in the training event itself. Panel members can be recruited from disability rights organizations, such as Independent Living Centers.

Training Apprentices

Individuals with disabilities can acquire some helpful training and consulting qualifications, which can serve training programs such as this one. Speakers with some experience may be included in an "apprentice" role or assistant leader role, which is an effective way to expand the cadre of leaders and resource people as well as the impact of this work. In addition to disabled individuals serving as panel members, they can also be workshop assistants

who handle registration, etc., which is an excellent way to train new trainers and increase workshop participants' exposure to disability.

Handling Emotionally Charged Issues

Disability training can raise sensitive issues for individuals with disabilities and medical and human service professionals. On occasion, some workshop participants in either of these categories may feel defensive or argumentative and express these feelings during the training. The trainer can state calmly that he or she is sorry if a comment has made anyone feel personally or professionally criticized. It is helpful to state simply that the goal of the workshop is not debating, but sharing information and allowing differing views to be expressed.

Workshop Facilitator's Guide

Preparation for Facilitators

To prepare for a training workshop presentation, facilitators must

- familiarize themselves fully with the training materials and the video *Access to Medical Care: Adults with Physical Disabilities*;
- arrange for appropriate audio-visual equipment;
- prepare handouts for distribution, including the following:
 - ❖ Fact Sheet: Medical Care and Disability Awareness - Key Points
 - ❖ Case Examples for Discussion (to be printed and cut apart for the exercise)
 - ❖ Workshop Handouts
 1. Definition of a Person with a Disability
 2. Barriers to Health Care
 3. How to Provide Quality Medical Care to Individuals with Disabilities
 4. Stimulus Questions: Applying Access Information and Rapport Skills
 - ❖ Evaluation Form

Workshop Agenda

Suggested format for a ninety-minute workshop, for up to twenty-five participants, is below. Each segment can be flexibly timed, as appropriate for the audience and time available.

1. Introductions (10 minutes)

Invite participants to introduce themselves and briefly share their interest in these issues. This will give the facilitators a sense of the audience's training needs, break the ice on the topic of disability, and acquaint participants with each other.

2. Goals Statement (5 minutes)

The facilitators state the goals for the training and disseminate handouts, which summarize and reinforce key points for participants.

3. Video and Questions (35 minutes)

View the twenty-five-minute video and invite questions and discussion. Participants may share reactions to the video's content and ask questions for clarification.

4. Case Exercises in Small Breakout Groups (20 minutes)

The cases presented in the video challenge participants to apply their knowledge about accommodating individuals with disabilities in medical settings and put into action their understanding of the requirements of the ADA. Participants are asked to break into groups of two or three people. Each group is given one case to consider, along with stimulus questions provided on Handout 4 of this curriculum. Participants are instructed to read the case aloud and then together address the stimulus questions. Participants are encouraged to brainstorm potential access needs of the case and develop a list of access and accommodation recommendations to report to the large group.

5. Case Reports and Discussion (15 minutes)

Small-group participants then return to the group to present recommendations for discussion. The time available and the size of the overall group determine how many participants may report their answers. (Recommended: five to ten minutes per small group of two or three individuals.) The facilitators will include reports on as many cases as time allows.

Each case raises crucial access and accommodation concerns for people with various disabilities. Following each small group's recommendation, the facilitators refer to and reinforce the appropriate ADA requirements. The facilitators offer clarification and, if necessary, correction of participants' misconceptions, as they arise with the small group's case recommendations. Facilitators can use the **Additional Case Considerations** for further discussion and clarification of participants' case recommendations.

6. Closing (5 minutes)

The facilitators refer to materials in the packet to highlight articles and resources of interest and request that participants fill out and submit **Evaluation** Forms.

Fact Sheet: Medical Care and Disability Awareness: Key Points

- 1. Individuals with disabilities require the same quality of medical service and preventive care** as individuals without disabilities, but they may be underserved and receive less than quality care.
- 2. Defining “health” as the absence of disability or chronic illness** negatively affects individuals with disabilities. Many lead active, fulfilling lives, which include work and community, sexual relationships and parenting, or could achieve these with appropriate community resources. Fortunately, many disabled individuals consider themselves healthy and well, which likely enhances their quality of life.
- 3.** While a disability doesn’t necessarily imply illness, some disabilities may lower the threshold to an array of secondary conditions. **Preventive care and early intervention can reduce complications.**
- 4. For accurate assessments, providers need to listen attentively to their patients with disabilities** in order to understand their background and functional needs. They also need to avoid stereotyped assumptions about disability and unnecessary referrals to specialists. A team approach works best to accommodate complex medical needs.
- 5.** Barriers to receiving quality health care include **physical/architectural barriers, communication barriers, attitudinal barriers, and social/economic policy barriers.** Understanding these barriers and obtaining accessibility training will be helpful for both medical and support staff. (See materials for technical information and social perspectives.)
- 6. Medical facilities and practitioners are required** by the ***Americans with Disabilities Act*** to provide access for people with disabilities to health care services. The law requires **reasonable accommodations**, meaning those that are **readily achievable** and do not present an **undue hardship** on the facility. Practitioners and facilities need to learn about and provide specific accommodations for people with the full range of disabilities.

7. **Advance access planning** can save time and improve the quality of care.
8. **Health Care Providers need to check accessibility** when referring patients to diagnostic testing and specialty clinics. They also need to check whether referred-to medical providers accept the patient's insurance.
9. **Some people with disabilities have an expertise** in their conditions, which should be respected and reinforced. Others, particularly newly disabled people, need training and support to become active partners in their care.

Workshop Handouts

Workshop Handout 1

Definition of a Person with a Disability from the *Americans with Disabilities Act*:

the term "disability" means, with respect to an individual,
(a) a physical or mental impairment that substantially limits one or more major life activities of such individual;
(b) a record of such an impairment; or
(c) being regarded as having such an impairment.

Major life activities include, but are not limited to, caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working.

Workshop Handout 2

Barriers to Health Care

Barriers that prevent access to health care can be

- physical/ architectural
- communicative
- attitudinal
- social/ economical

Workshop Handout 3

How to Provide Quality Medical Care to Individuals with Disabilities

When treating persons with disabilities, remember to

- talk directly to them, the patients, not to someone who accompanies them;
- avoid making assumptions;
- ask how you can help them and respect their answers;
- ensure that educational materials are easily accessible;
- allow time for history taking and thorough examination.

When treating persons who are blind or visually impaired,

- always verbally identify yourself when you approach and do not leave without letting them know;
- always ask how they would like to be assisted;
- be prepared to provide written materials in an auditory format, on computer disc, in Braille, or in large print;
- verbally explain procedures before beginning treatment and ask your patients if they have any questions;
- in the exam room, indicate where they may leave their clothing and personal affects and do not move these without letting them know;
- train your staff to be welcoming and respectful and to describe the office, including doors, steps, or ramps;
- remember that service dogs are legally allowed in medical facilities. Do not pet or distract guide dogs and respect the blind persons' instructions regarding their guide dogs.

When treating persons who have a hearing loss,

- ask how to best communicate;
- be prepared to provide written educational materials;
- do not talk to them from a distance or from another room;
- look at them while speaking and make sure they can see your mouth;

- avoid shouting, exaggerating mouth movements, and rapid talk;
- speak in a normal tone of voice, but clearly;
- minimize background noise and glare.

When treating persons who are Deaf,

- ask them how best to communicate;
- remember that communication needs vary from person to person and from situation to situation;
- if requested, provide qualified ASL interpreting or realtime captioning services for effective communication;
- be aware that patients cannot be charged for ASL interpreting or realtime captioning services;
- know that family members should not be pressured to function as ASL interpreters to save time or expense.

When treating persons who are wheelchair users,

- provide access to exam areas;
- provide assistance, if necessary, for a full and complete exam, even if it requires more time or assistance;
- respect personal space, including wheelchairs and assistive devices;
- avoid propelling wheelchair unless asked to do so;
- obtain adjustable exam tables for your facility, if possible.

When treating persons with developmental disabilities,

- communicate with them about what you are doing during an exam. If you are unsure how best and most appropriately to communicate with developmentally disabled persons, seek additional training or consultation.
- where appropriate,
 - provide information in plain language,
 - work within the patient's attention span,
 - allow more time for appointments,

- use a flexible schedule to minimize the time the patient has to spend in the waiting room,
- schedule several appointments to conduct exams to minimize the patient's frustration.
- provide access to the full range of preventive care.
- Refer patients to the full range of preventive, reproductive and sexual health care services and, when appropriate, mental health or substance abuse services.
- ask them, their family members, or guardians for suggestions about what to keep in mind when treating them — and note the solutions in their charts. Then anticipate those needs prior to their next visits.

Workshop Handout 4

Stimulus Questions: Applying Access Information and Rapport Skills

1. Access Barriers to the Facility

- a) What access issues might arise for this patient? Consider
 - transit to and from the appointment;
 - physical/architectural barriers inside the facility;
 - the examination, diagnostic procedures, and follow-up or referrals.
- b) What difficulties might arise for the facility's staff in meeting this disabled person's access needs?
- c) What information could assist the medical provider in advance, and how might this be obtained?
- d) What auxiliary aids or services might be required to facilitate access?
- e) What assistance or safety precautions might be required from staff or the disabled person's companion or personal assistant, and how would this be arranged?

2. Attitudinal, Social and Economic Policy Barriers

- a) What attitudinal or social and economic policy barriers might this disabled person encounter in a medical situation?
- b) What issues regarding dignity, privacy, or autonomy might arise?
- c) Could this disabled person's care or wellness potentially be compromised by limitations in Medicaid/Medicare coverage?

3. Rapport and Interview

- a) What issues might arise regarding communicating or establishing rapport?
- b) What medical history questions need to be answered about this person's disabling condition(s) to adequately address presenting symptoms?
- c) What safeguards or reassurance could be offered to help engender an atmosphere of trust and safety that this patient would not be exploited as a guinea pig or disrespected as a person with a disability?

4. Exam, Diagnosis, and Treatment

- a) What access or rapport issues might arise during the diagnosis or treatment process?
- b) What factors might need to be addressed to improve this disabled person's adherence to the treatment plan?
- c) What assistance or accommodations might be appropriate in administering medications?

5. Referrals

- a) What referrals might be useful for this patient? What stereotyped assumptions about individuals with disabilities might lead to an inappropriate referral of this disabled person to a specialist?
- b) What are clear indicators that a specialty referral would be appropriate for this disabled person?
- c) In referring this patient for diagnostic testing, what access, insurance coverage, HIPPA, confidentiality or privacy, or medical records-related difficulties might arise?
- d) Can crucial information about this patient be appropriately flagged in the medical chart? How?

6. Follow-Up Care

- a) What barriers to obtaining follow-up care might arise for this patient?
- b) What barriers might arise in informing this disabled person of diagnostic test results?

Workshop Handout 5
Evaluation Form

1. After completing the training, did you gain a better understanding of the health care needs of individuals with disabilities?

_____ Yes _____ Somewhat _____ No

Comments _____

2. Do you think the training adequately addressed essential issues and barriers to serving this population?

_____ Yes _____ Somewhat _____ No

Comments: _____

3. Do you feel more confident in requesting appropriate, accessible care (select one)?

_____ Very confident

_____ Somewhat confident

_____ Not confident

_____ Other (please explain) _____

4. After this training, do you think you have improved knowledge about the following: (select "yes" or "no")?

Yes No

___ ___ requesting specific reasonable accommodations in your facility?

___ ___ talking with professionals and support staff about providing these?

___ ___ complying with the *Americans with Disabilities Act* requirements?

Comments: _____

5. What additional resources or training would you need in order to feel confident with any of the above?

6. What suggestions do you have to improve the training workshop?

Thank you!

Cases Examples for Discussion

These case examples are presented as a basis for discussion. They are designed to emphasize establishing rapport and developing appropriate access and accommodation for a clinical exam.

Workshop participants may also be encouraged to offer their own case examples in addition to the ones listed below, or be notified in advance of the workshop to prepare and bring case examples.

For the workshop's small-group exercise, cases can be printed out on a separate page, cut apart, and be distributed one each to the small breakout groups, along with a copy of the stimulus questions.

1.

Ron T. is a 39-year-old man with a C6 spinal-cord injury, who is employed as a computer software designer. He drives his own van and uses a powered wheelchair. He has just joined his employer's new health plan, which referred him to your clinic for an annual physical.

2.

Sarah M. is a 31-year-old legally blind woman. She is married and the mother of a four-year-old, whom she brings along to the appointment. She has a skin rash on her arms and abdomen and complains of itching. She indicates that her sighted husband described the appearance of the rash to her. Sarah is concerned about the rash being contagious to her child and her being able to monitor the rash's healing.

3.

Jake B. is a 57-year-old paraplegic man with post-polio from childhood who uses a wheelchair. He is employed as a dispatcher for a trucking company. He complains of irritation in the anal area and occasional blood on the toilet paper. Jake is not sure if he has ever had hemorrhoids. He is unable to stand.

4.

Lin P. has severe rheumatoid arthritis. She is 49 years old, lives alone, and walks with two canes. Occasionally, she uses a manual wheelchair for longer distances. Lin presents with a fever of 99.1 Fahrenheit and reports nausea and vomiting the previous night.

5.

Daniel L. is a 68-year-old man with right hemiplegia from an aneurysm, five years post incident. He has a significant degree of dysarthria; he ambulates using a four-point cane. Daniel complains of mild breathing difficulties keeping him up at night, especially when he is lying down. He also has a history of allergies.

6.

Donna J. is a 62-year-old Deaf woman, who grew up in a family with two Deaf parents and one hearing sister. Donna's primary language is ASL. She works as an office manager in a mail-order business. She complains of abdominal pain. She lipreads fairly well and uses a notebook to briefly jot down her thoughts, but requests an ASL interpreter if she will be required to undergo any diagnostic tests because she is afraid of not fully understanding what might be happening.

7.

Mario T. has achondroplasia. He is 3 feet, 9 inches tall, 46 years old, and ambulates independently. He works as an administrator at a community college. Mario presents with joint pain in his shoulder, saying it is interfering with his computer work.

8.

Alexander F. is a 29-year-old man with Becker’s Muscular Dystrophy. He is married with two children, describes himself as a disability activist, and works at an Independent Living Center. Alexander says he has had headaches and difficulty sleeping for two months.

9.

Michelle S. is a 31-year-old full-time graduate student with moderately severe cerebral palsy, including significant dysarthria and mobility impairment. She is able to walk, but comes into the clinic in her manual wheelchair, which she uses sometimes. She lives in the accessible student dorm on campus. Michelle complains of a sore throat and fatigue, which have bothered her for the last ten days.

10.

Sam M. is a 39-year-old man with Asperger’s Syndrome, with moderate attention deficit disorder (ADD). He is employed part-time as a bagger in a grocery store, has a driver’s license, and owns his own car. He lives with a roommate in an apartment, and has a legal guardian, who is not a family member. Sam regularly plays basketball at the YMCA and becomes mildly injured while playing. He is complaining of hip and leg pain.

11.

Risa L. is 24-year-old woman with Down Syndrome who attends a community college program for developmentally delayed individuals, training to become a daycare provider. She has a boyfriend, who is also developmentally disabled, whom she plans to marry in a year. Risa comes to your clinic for an annual check-up, and inquires about birth control and STD protection.

Additional Case Considerations

(To be used in case feedback discussion, following the small group's access and accommodation recommendations.)

For Mobility-Impaired Individuals, consider the following issues:

- Is there accessible parking, including wheelchair van parking, which means room for the lift or ramp to deploy, not just car-width spots?
- Is there an accessible entrance to the facility? Is it clearly marked?
- Are exam rooms accessible to wheelchair users?
- Are reception-area personnel and medical staff educated to be non-patronizing and to assume that a person who uses a wheelchair is potentially fully employed, competent, and knowledgeable about self-care?
- Is there an adjustable exam table to allow a full exam?
- Is there a policy regarding provision of personal assistance for transferring to an exam table and dressing and undressing? If so, are disabled patients informed of this policy?
- Are medical staff adequately informed about the disabled person's condition? For example, are they aware of spinal-cord injury-related concerns, such as dysreflexia, skin care, bladder and bowel care, and personal assistance services?
- Is a sexual history taken? (Often neglected due to the stereotype of asexuality.)
- Is the pharmacy able to supply medication in easy-to-open containers accessible to quadriplegic individuals?
- If referral for diagnostic testing is made, can the chart be appropriately flagged to inform specialists or diagnosticians of wheelchair-access needs?

For Blind or Visually Impaired Individuals, consider the following issues:

- Are there Braille markings on elevators?
- Are resource people available in the lobby to assist blind people?
Are they trained to assist in orienting a blind person to locate specific areas in the facility?
- Are reception-area personnel and medical staff taught to be non-patronizing and to assume that a blind person can be, for example, a competent parent, fully employed, and an independent individual?
- Are medical and non-medical staff trained to verbally explain procedures?
- Are patient-education materials available in alternative formats, such as large print, audio cassette, Braille, or computer disk?
- Do reception-area personnel and medical staff know not to assume or expect a sighted child accompanying a blind parent to be a guide or guardian in any way?
- Does the pharmacy have Braille labeling capability, and if not, who is available to verbally instruct the patient?

For Speech-Impaired Individuals, consider the following issues:

- Are medical and non-medical staff trained to be respectful and non-patronizing?
- Are medical and non-medical staff trained to be patient, not to complete sentences for or second-guess the patient?
- Is there sufficient time allowed for speech-impaired individuals to communicate verbally or via a word board or computer display?
- Is there adequate time scheduled during the appointment for the patient to adequately communicate without pressure to hurry?
- Do staff know to directly address the disabled person who is the patient and not a companion? (Unless the companion is indeed a guardian, which should be clearly determined, not assumed.)

For Individuals with Hearing Loss, consider the following questions:

- Do reception-area personnel and medical staff know to differentiate between hearing-impaired individuals (hard-of-hearing) and those who are culturally Deaf (functionally deaf)?⁵
- Do reception-area personnel and medical staff know that the vast majority (97.5%) of all individuals who have a hearing loss use spoken language skills? Only a small minority (2.5%) uses American Sign Language (ASL) as a primary means of communication.⁶
- Do medical and non-medical staff know that English is a second language to individuals who use ASL as their primary language?
- Are medical and non-medical staff aware of facility policy, community resources, and contact information regarding amplification devices or ASL interpreting or realtime captioning services?
- Are staff familiar with TDDs (Telecommunication Devices for the Deaf) and available communication relay services, such as Video Relay, CapTel, or WebCapTel?
- Are qualified interpreting or realtime captioning services appropriately contacted and scheduled?
- Are medical and non-medical staff aware that they may not charge the patient for realtime captioning or ASL interpreting services?
- Do staff know that family members should not be pressured to function as sign-language interpreters to save time or expense?
- Are medical and non-medical staff trained to be patient, respectful, and non-patronizing, not to complete sentences or second-guess the patient, and directly address the patient and not a companion, real-time captioner, or sign-language interpreter?
- Are staff ready to provide auxiliary aids and services? These include visual aids, written instruction, or communication via writing if necessary.

⁵ www.hearingloss.org/docs/EEOC%20Paper.doc

http://www.audiologyawareness.com/hearinfo_impairdeaf.asp

⁶ <http://research.gallaudet.edu/Demographics/deaf-US.php>

For Developmentally Disabled Individuals, consider the following issues:

- Are staff trained to be respectful and non-patronizing, and to use plain language and clear explanations of procedures and health issues?
- Are reception and nursing staff able to assist developmentally disabled patients to enter and negotiate exam rooms and provide any necessary assistance with undressing or other relevant procedures?
- Are staff trained to recognize and override the culture's assumptions that people with developmental disabilities are asexual?
- Are staff made aware that developmentally disabled adults, and adolescents, where appropriate, need and are entitled to information about sexuality, reproductive health, protection from and testing for sexually transmitted disease and access to birth control?
- Are medical and social work staff aware that they are mandated reporters of abuse, and that the rate of sexual and other kinds of abuse is higher for people with developmental disabilities?
- Are staff instructed to treat family members, caregivers, and personal assistants with relaxed appreciation and respect and to avoid stereotypes of family members as being "saints" or "amazing."
- Are medical staff aware of common appropriate accommodations for patients with developmental disabilities, such as providing information in plain language, being aware of learning styles, accommodating attention span, and allowing more time for appointments and scheduling flexibility?

Tips for Individuals with Disabilities on Expecting and Receiving Quality Medical Care

- ❖ Remember that you are in charge of your medical care. Regard your medical doctor and other health care providers as consultants who are employed by you.
- ❖ Don't accept hurtful or inappropriate interactions. If confronting your physician seems difficult, try role-playing first with friends to help you assert yourself.
- ❖ Take a friend or assistant with you to take notes and provide support. Make sure the provider knows that the friend, or an interpreter or personal assistant, if you use one, is not your guardian and that all communication should be directed at you.
- ❖ Prior to the appointment, write down any questions for your provider, in order of importance. Bring this list with you to the exam room. Ask your friend or assistant to take notes during the appointment because you may be distracted and forget important details.
- ❖ Call ahead to ask about wheelchair access or other accessibility concerns. If you require assistance transferring to the exam table or disrobing, ask if your assistant or friend may help you or if the medical provider has other policies about assistance. Ask about additional time for the appointment if you have a speech impairment or need extra time for personal assistance.
- ❖ To find a good medical doctor, ask individuals you trust to refer you to their health care providers. Avoid the web, phone book, or other listings. Before scheduling an appointment, call first to ask if the health care provider has experience with your disability.
- ❖ Ask your general practitioner to find out about a specialist's experience or willingness to treat disabled people before referring you for an appointment.

- ❖ Don't be "patient" with mistreatment, even from medical doctors. Consider whether you think you could get the provider or his or her staff to change their attitude or behavior towards you as a disabled person. It's tricky to tell if change is possible. It's probably best to change health care providers if you feel frightened, threatened, or coerced.
- ❖ If you feel "patronized" or not respected as a capable adult, you might be able to challenge this attitude by pointing it out to the provider. Ask him or her to treat you like he or she does any other adult patient.
- ❖ Insist that your friend or personal assistant be allowed in the examining room with you. If your friend or assistant is asked to leave the exam room, require an adequate explanation.
- ❖ Expect your physician to be willing to learn from you about your disability.
- ❖ Insist that explanations about treatment be understandable. For example, ask your medical doctor to draw a picture or give you a written explanation that you can understand.
- ❖ If you appreciate the way your physician treats you, let him or her know. Good medical doctors deserve to be acknowledged. Refer others to that doctor.

Downloadable Comprehensive Guides and E-Courses on Disability Issues, Cultural Competence and the *Americans with Disabilities Act*

The downloadable guides listed below provide excellent resources for training and individual instruction in (a) essential cultural competence issues for health care providers serving patients with disabilities; and (b) meeting the requirements of the *Americans with Disabilities Act* (ADA). They also feature extensive bibliographies on pertinent research and training materials.

Removing Barriers: Tips and Strategies to Promote Accessible Communication

This comprehensive guide from the North Carolina Office on Disability and Health addresses disability awareness; communication aids and alternative formats, including print materials, audio tapes, computer access, and video relay and captioning services; and how to make materials accessible to individuals with a range of disabilities. It also includes a useful glossary. The guide can be read online or downloaded in PDF.

<http://www.fpg.unc.edu/~ncodh/htmls/rbtipsandstrategies.htm>

<http://www.fpg.unc.edu/~ncodh/pdfs/rbtipsandstrategies.pdf>

Removing Barriers to Health Care: A Guide for Health Professionals

Another excellent guide from the North Carolina Office on Disability and Health that addresses architectural access issues for health care facilities, including design standards established by the ADA. The guide can be read online or downloaded in PDF. Note that the online version does not show a title. The title of the PDF reads "How usable are your health care services to people with disabilities?"

<http://www.fpg.unc.edu/~ncodh/htmls/rbhealthcare.htm>

<http://www.fpg.unc.edu/~ncodh/pdfs/rbhealthcare.pdf>

Access to Medical Care for Individuals with Mobility Disabilities

This guide combines text and detailed illustrations to thoroughly inform about providing access and quality care to individuals with mobility disabilities. The guide has four parts and the first one gives an overview of the ADA and how the law applies to health care providers. The second part

answers FAQs; the third one focuses on accessible examination rooms; and the fourth part concentrates on accessible medical equipment.

http://www.ada.gov/medcare_mobility_ta/medcare_ta.htm#part2

A Family Physician's Practical Guide to Culturally Competent Care

While not specifically focused on physical disability, this e-learning course from the Office of Minority Health (part of the U.S. Department of Health and Human Services) addresses essential principles of care that are central to providing quality medical care for people with disabilities, including those from multi-cultural backgrounds.

<https://www.thinkculturalhealth.hhs.gov/>

Improving Health Care for Persons Who Have Developmental Disabilities

A valuable resource from the Matheny Institute for Research in Developmental Disabilities, Matheny Medical and Educational Center, that is geared towards health care educators training future health care providers in giving culturally sensitive and effective medical care to individuals with developmental disabilities. The website features multimedia presentations and downloadable documents.

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

Let's Talk About Health: What Every Woman Should Know (Workbook and DVD)

A short educational film (DVD) and workbook from the Arc of New Jersey's Women's Health Project for women with developmental disabilities to become knowledgeable about and comfortable with their bodies and health care procedures and services. The DVD and workbook are tools to be used by parents, providers, and educators.

http://www.arcnj.org/programs/mainstreaming_medical.html

Medical Offices and the ADA

An excellent resource, in question-and-answer format, from the Council of Better Business Bureaus and the Disability Rights Education and Defense Fund that succinctly answers common questions about the ADA and health care providers.

http://www.dredf.org/ADA/medical_offices.shtml

Oral Health Care for Persons with Disabilities

An online continuing-education course by the College of Dentistry, University of Florida, with information on how to provide oral care to people with various types of disabilities. The course is available in Spanish and Turkish.

<http://www.dental.ufl.edu/Faculty/Pburtner/Disabilities/Default.htm>

Pre-service Health Training for Primary Care Providers of Women's Health Care

The Pre-service Health Training (PHT) modules were designed to educate students entering the health care field and practicing primary health care providers about working with women who have developmental disabilities. The training modules include a guide for instructors and one for students.

<http://womenshealth.phtmodules.net/default.aspx>

Reproductive Health Care for Women with Disabilities

An excellent six-part tutorial that was created by the American Congress of Obstetricians & Gynecologists (ACOG) for health care clinicians who work with women with disabilities. The tutorial is available on ACOG's interactive website as a recorded slide program (not captioned, though) or a PowerPoint with scripted notes.

http://www.acog.org/departments/dept_notice.cfm?recno=38&bulletin=4526

Woman Be Healthy: A Curriculum for Women with Mental Retardation and Other Developmental Disabilities

This training curriculum, from the North Carolina Office on Disability and Health, was developed to help women with intellectual and other developmental disabilities become self-advocates in their own health care. The three main categories of the curriculum focus on health education, anxiety reduction, and assertiveness and empowerment.

The curriculum can be read online or downloaded as a PDF.

<http://www.fpg.unc.edu/~ncodh/htmls/wbhealthy.htm>

<http://www.fpg.unc.edu/~ncodh/pdfs/wbhealthy.pdf>

Annotated Online Resources for Health Care Providers Serving People with Disabilities

Health Care; Legal Issues and the ADA; Information Portals; and Additional Training Programs and Materials Websites

These searchable online resources provide a wealth of information on specific disabling conditions, sub-constituencies and disability issues. They offer relevant medical, disability rights and Independent Living resources, listed by category: Health Care; Legal Issues and the *Americans with Disabilities Act*; Information Portals, and Additional Training Programs and Materials.

Health Care

A Provider's Guide for the Care of Women with Physical Disabilities and Chronic Health Conditions

Another excellent resource from the North Carolina Office on Disability and Health, this revised guide, which is dedicated to Dr. Sandra Welner, is designed for clinicians to improve their knowledge and practice in providing care to women with physical disabilities and chronic medical conditions. It includes information on access to general medical care, removing common barriers, and comprehensive reproductive health care.

<http://www.fpg.unc.edu/~ncodh/pdfs/providersguide.pdf>

Depression and Disability: A Practical Guide

This compact guide, available from the North Carolina Office on Disability and Health and put together by Dr. Karla Thompson, defines depression, points out its symptoms, addresses risk factors for depression, discusses how it can be treated, and lists a carefully selected collection of resources. This guide is an excellent resource for health educators, service providers, and program planners.

<http://www.fpg.unc.edu/~ncodh/pdfs/depression.pdf>

Sexual Health Network: Disability and Illness

The Sexual Health Network has an extensive section focusing on disability and chronic conditions that offers individuals with disabilities and those who love and care for them easily accessible information on sexuality, sex education, health care, counseling, therapy, support services, and sexual health and other resources. The site also includes a Q&A section.

<http://www.sexualhealth.com/channel/view/disability-illness/>

Legal Issues and the ADA

Disability Rights Education and Defense Fund (DREDF)

DREDF is a national law and policy center dedicated to protecting and advancing the civil rights of people with disabilities through legislation, litigation, advocacy, technical assistance, and education and training of attorneys, advocates, persons with disabilities, and parents of children with disabilities.

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

Disability Rights Advocates (DRA)

DRA is a legal nonprofit that advocates, negotiates, and litigates to ensure and enforce the right of disabled individuals to have the same access to health care, transportation, technology, education, and employment as individuals without disabilities.

<http://dralegal.org/>

National Association of the Deaf (NAD) Law Center

“Questions and Answers for Health Care Providers” is a memo in frequently-asked-questions (FAQs) format from NAD’s Law and Advocacy Center that addresses the access rights of Deaf and hard-of-hearing individuals to health care.

<http://nad.org/issues/health-care/providers/questions-and-answers>

Information Portals

Annotated Bibliography: Sexuality and Disability

A bibliography, compiled and annotated by the Sexual Information and Education Council of the United States (SIECUS), that represents a cross section of available resources on physical and mental disability as well as chronic illness.

<http://www.siecus.org/index.cfm?fuseaction=page.viewPage&PageID=580&varuniqueuserid=72030761608>

Communications Information Access Center

This site offers information on realtime captioning, or Communication Access Realtime Translation (CART), how to locate, and what to expect from a CART provider. CART is an accommodation for individuals with hearing loss whose primary means of communication is not American Sign Language.

<http://www.cart-info.org/>

National Women's Health Information Center – Women with Disabilities

Women with disabilities, caretakers, health professionals, and researchers will find information and resources on different types of disabilities, abuse, access to healthcare, breast health, financial assistance, older and minority women with disabilities, parenting, reproductive health, and substance abuse. The site also lists a toll-free information and referral hotline.

<http://womenshealth.gov/search/cgi-bin/query-meta.exe?input-form=simple-womenshealth&v%3Asources=womenshealth-bundle&v%3Aproject=womenshealth&query=women+with+disabilities&search=Search>

Medline Plus: Disabilities

A service from the U.S. National Library of Medicine and the National Institutes of Health that provides extensive links to national resources; directories; specific disability conditions; treatment management options; clinical trials; patient/consumer and provider organizations; law and policy information; financial aspects; statistics; and recent articles and issues concerning disabled women and children with disabilities. The site is updated daily.

<http://www.nlm.nih.gov/medlineplus/disabilities.html>

Registry of Interpreters for the Deaf (RID)

RID is a national [membership](#) organization of professionals who provide sign language interpreting/transliterating services for individuals with hearing loss whose primary means of communication is American Sign Language.

<http://www.rid.org>

Removing Barriers Resources

An excellent resource list, compiled by the North Carolina Office on Disability, that has links to sites focusing on accessible design, ADA reinforcement and compliance, and disability awareness and independent living.

<http://www.fpg.unc.edu/~ncodh/removingbarriers/removingbarriersresources.cfm>

Substance Abuse and Mental Health Services Administration (SAMHSA)

This site provides links to further directories and resources on suicide prevention, depression, and specific conditions; newsroom and current articles; and conferences and events. SAMSHA is part of the U.S. Department of Health and Human Services and this site is geared towards users of mental health services and their families, the general public, policy makers, providers, and the media. A toll-free number is listed to access information via phone.

<http://mentalhealth.samhsa.gov/>

Additional Training Programs and Materials

Program Development Associates (PDA)

PDA provides training materials for professionals and consumers about disability. Topics include disability awareness, advocacy, developmental and learning disabilities, special education, physical disabilities, mental health, assistive technology, and vocational rehabilitation.

<http://www.disabilitytraining.com/>

Through the Looking Glass (Parents and Children with Disabilities)

Through the Looking Glass (TLG), a California-based nonprofit community organization, pioneered clinical and supportive services, early intervention, and training and research. TLG serves families with members who have a disability or medical issues.

<http://www.lookingglass.org/home>

World Institute on Disability (WID)

WID is a nonprofit disability research, training and public policy center in Oakland, CA, promoting civil rights and inclusion of individuals with disabilities into all spheres of life. WID offers a Curriculum on Abuse Prevention and Empowerment (CAPE) for people with disabilities living independently, services providers, parents, and allies of people with disabilities.

<http://www.wid.org>

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