Advice from People with Disabilities on Providing Quality Health Care

---

What Health Care Providers Really Need to Know

Compiled by:

Champaign County Health Care Consumers

Disability Rights Task Force

Summer 2008

This information was compiled by: The *Disability Rights Task Force* (DRTF).
DRTF is a group led by people with disabilities, dedicated to working with health care providers to improve health care accessibility and services for patients with disabilities.

DRTF is a task force of Champaign County Health Care Consumers (CCHCC), a citizen action organization working to create meaningful reforms in the health care system through the active involvement of consumers.

For more information, please contact CCHCC:
44 E. Main Street, Suite 208, Champaign, IL 61820
(217) 352-6533 • cchcc@healthcareconsumers.org • www.healthcareconsumers.org

Advice from People with Disabilities on Providing Quality Health Care

What Health Care Providers Really Need to Know

Introduction

As people with disabilities, our desire is to advise health care providers about how they can best serve people with disabilities. We are people with disabilities who have our own experiences with health care. As a result of these experiences, we have compiled the advice presented in this handout in order to provide concrete and helpful information for health care providers. Information in this handout is organized into the following categories: 1) Communicating with People with Various Disabilities, 2) Basic Sensitivity, 3) Transfers, 4) Health Care Providers' Equipment, 5) Environment, 6) Architectural, 7) Common Areas, and 8) Staff Training: Tips for Managers and Trainers.

The single most important piece of advice we have to share, and the concept that underlies the various sections of this document, is that people with disabilities should be treated *as people.* We should be afforded all the respect and dignity that is given to any other person. *We are not defined by our disabilities, but have needs and preferences that are unique to each of us.* This document is not meant to be a checklist, but, rather, an introduction to a way of thinking, with concrete advice and examples about how to work most effectively with people with disabilities who are seeking health care.

The Disability Rights Task Force of Champaign County Health Care Consumers (CCHCC) is providing this handout in order to help improve health care for people with disabilities. However, the benefits of the advice in this handout are not just to the patient, but also to the health care provider. Better communication with people with disabilities can result in better treatment outcomes, and a reduction in workplace injuries for health care provider staff (for example, working with the patient to do a transfer can help reduce unnecessary strain and accidents). Last, but not least, we want to emphasize that this handout is offered in a good faith spirit of cooperation, with the knowledge that health care providers are likewise invested in, and dedicated to providing the highest quality care to their patients.

This project is dedicated to the memory of Lisa Busjahn and Bill Mueller, devoted and passionate activists for health care justice and disability rights.

1. Communicating with People with Various Disabilities:

Communicating with people with disabilities should be no different than communicating with any other individuals. Communication that is based on courtesy, respect, patience, and professionalism will enhance any interaction and will result in greater understanding and better quality of health care and outcomes for the patient.

For all disabilities:

- Treat all adults as adults. Do not be condescending or talk down to the person. If their disability necessitates, you may need to use simple language, but do not assume a person cannot understand you.
- Always speak directly to the patient, not his or her interpreter, assistant, or family member.
- Do not take offense or act impatiently when someone asks you to repeat something they did not understand.
- If someone has a title such as Reverend, Doctor, etc., show respect by using that title.
- Treat all people with courtesy, respect, patience, and professionalism – even if they behave in ways that may frustrate you. It is important to be aware that many people have "invisible" disabilities that may contribute to difficult interpersonal interactions. (*For more information about "invisible" disabilities, and how to communicate with people who may have "invisible" disabilities, please see the end of this section.)*

For speech disabilities:

- When talking to someone who has a speech issue, relax and think of it as an accent. Just as when you speak with a person who has an accent, you need to listen to the person in order to "get the hang" of how they speak. Do not pretend to understand what someone is saying. Repeat what you understood, and ask for repetition for what you did not understand.
- Do not use simpler words or change your tone of voice unless asked to do so.
- Remember that speech impairment does not equal mental impairment.
- Have communication boards available and easily accessible.

For cognitive disabilities:

- If a patient has an obvious mental impairment, speak with the patient. They will often signal their support person if they cannot answer a question. Staff need to be careful listeners.

For hearing disabilities:

- When calling names, realize some people cannot hear you. A better system for calling people forward may be necessary.
- Speak directly to the person so they can see your face. Do not cover your mouth. Do not yell at them, as they still will not hear you. Have written materials available to pass along to the person that explain what you are trying to say.
- Pointing is also acceptable in deaf culture.
- Know how to reach an interpreter if needed.

For vision disabilities:

- Use large print on bills and other hospital or medical communications for those who need it.
- When talking to a person who is blind, use specific language like "two feet to your right," instead of non-specific language like "over there."
- All medical documentation should be made accessible in some way, to people who cannot read standard print. Health care workers reading documents should read only the text in the document, not summarize or add their own comments, unless the person with the disability asks them to.

Communicating with people with "invisible" disabilities:

"Hidden" or "invisible" disabilities are those disabilities that have little or no visible indicators and are not readily apparent. These disabilities are the result of medical conditions (such as diabetes, chronic pain, HIV/AIDS, etc.) and/or psychological and cognitive conditions (such as depression, autism, ADHD, etc.). *"Hidden" and "invisible" disabilities are actually the most common form of disability.* Although both types of conditions resulting in "invisible" disabilities can affect an individual's life, people with psychological disabilities may be less likely to reveal their disabling conditions due to fear of societal stigma.

People with "invisible" disabilities may sometimes react in ways that are inappropriate or unpleasant, as a result of their disabling condition. As a result, their behaviors may be misinterpreted or misunderstood and others may react with frustration, hostility, annoyance, impatience, or other forms of unprofessional and unhelpful behavior. Conversely, some individuals with "invisible" disabilities may respond in overly compliant and acquiescent ways and seem like "easy" patients who do not challenge or ask questions. ***A health care provider should not assume that a person does not have a disability – especially if an interaction seems strange or difficult.***

The following are “rules of etiquette” to help health care providers interact productively with people with “invisible” disabilities.

- Do not assume that the individual does not have a disability.
- Include the individual in the decision-making process.
- If the patient requests that some other support person be allowed to be with them, honor this request. The patient may have anxiety or difficulties understanding or remembering information, and need to have someone assist them or support them.
- If a person appears drunk, do not assume they have been drinking. Their behavior may be a symptom of an underlying health condition (such as Cerebral Palsy).
- Be understanding and patient if the person becomes emotional.
- If the person makes a mistake, correct them in a respectful manner.
- Maintain your composure and professionalism; do not react with frustration or hostility.
- Do not hurry or rush the patient.
- If the individual becomes upset, ask them why they are upset – the reason may not be obvious.
- Pay attention to non-verbal cues.
- Respond politely to a request.
- Try to face the person while speaking to them.
- If you do not understand what the individual is saying, or why they are saying something, ask them respectfully to repeat themselves or to explain what they’ve said.
- If someone does not understand what you have said, try rephrasing your statement.
- Do not use a patronizing tone of voice.
- Break down complex information or instructions into smaller parts; check in with the individual to make sure they are understanding and can follow those instructions.
- Be courteous, respectful, patient and professional, even in frustrating or difficult situations.

2. Basic Sensitivity

About the person’s medical equipment:

- Never move a wheelchair (or other mobility device) away from the patient without asking first. Some people get very uncomfortable if their chair is out of reach even if they have no intention of getting out of bed.
- Any equipment a person uses (such as a wheelchair, guide cane, crutch, or guide animal) is part of that person’s personal space. Do not touch, push, pull, lean on or

otherwise interact with the individual's equipment unless requested to do so. Never use someone's personal wheelchair for another patient.

About asking for help:

- Do not assume that a patient does not need help if they are asking for help. If the person is asking for help, even if you do not see an obvious need, do your best to give them the help they request. They are asking for a reason, even though that reason may not seem obvious.
- If you think the person may need help, feel free to ask them if they do need help or assistance. If they do not, they will let you know.

Accommodations:

- Departments should be geared towards providing the best service for each individual patient. For example, accommodation of some sort (such as a plastic device in the toilet to catch urine) needs to be made when someone is not able to hold a specimen cup for a urine sample. Orthopedic departments should be comfortable working with different bone conditions or injuries, not just sports injuries.
- Remember that doctors can often write orders to allow something specific, such as a particular accommodation, in a medical setting for a patient.

Discharging the patient from the hospital:

- A common fear among many people with disabilities is that they will be sent to nursing homes after going to the hospital. This fear is real, as many of us have experienced this or have friends who have. Many of us DO NOT want to go to nursing homes. Listen to your patients and their desires. When it comes to our disabilities we know how to make life work. We need your advice on the specific reason we came to get health care. Please focus on giving us the best care, just like any other patient. In addition, avoid the assumption that a person with a disability will be best cared for in a nursing home.

3. Transfers

Transfers can be a source of tremendous frustration, and injury, to both patients and health care providers. Following these guidelines can help prevent patient injury, *as well as workplace injury for health care provider staff.*

How to help:

- Ask the patient how it is best to transfer them or if they can do it themselves. Remember that the patient is an expert in his/her own needs, and as a person with a disability, probably has a lot of experience dealing with transfers.
- When a person asks for assistance, do not ask why – ask *how.*
- Never grab a person without asking first. This can throw off a person's balance, make it difficult for the person to move, and increase the possibility of injury.
- Remember that it is the facility's responsibility to transfer the patient. The patient is not required to bring a family member or personal assistant. Even if the patient does bring someone to assist, the staff should be prepared to assist as well.

Important transfer devices:

- All nurses/CNAs/therapists should know where the Hoyer lift is stored and how to use it.
- Transfer boards and gait belts are also helpful to have available.

4. Health Care Providers' Equipment

Whenever possible, health care providers should strive to have the most accessible medical equipment possible. Accessible equipment, such as exam tables that go very low, are a benefit to all patients, including patients who may not have a disability, but may be temporarily unable to move in certain ways as a result of an injury or another medical condition.

Medical equipment is expensive, so sometimes a health care provider's best opportunity to obtain accessible medical equipment is when purchasing new equipment for a renovation or new construction. The Disability Rights Task Force has conducted extensive research into accessible medical equipment and is available to share information about accessible medical equipment with any provider who is interested.

- *Adjustable exam tables* (that go as low as 16 inches) are the number one item needed in most facilities. They help the person who is disabled, elderly, or short statured to get on the exam table. These can reduce staff injuries by eliminating the need to lift patients. (The same is true for x-ray tables.)
    - Exam tables also should be wider (to assist individuals who are larger or who have spasms or tremors), and have a moveable rail (to assist patients in moving or prevent them from falling off the table).
- *Therapy equipment* is often, unfortunately, not usable by people with disabilities.

- *Mammography machines* often do not go low enough for someone who uses a wheelchair. Accommodating equipment, such as a moveable ramp, needs to be available.
- *Water fountains* are inaccessible for most people in wheelchairs. Inaccessibility of water fountains can be resolved by putting a paper cup dispenser next to the fountain.
- *Bed scales* can be used to weigh individuals who have trouble balancing on a regular weight scale. (In addition, there are other kinds of scales that allow the patient to be seated while weighing, or that allow the patient to be weighed while in their wheelchair. Having a range of options would be helpful.)
- *Bone density scans* do not work on people who weigh more than 270 pounds. Staff should be prepared to explain why and offer another option.
- *Make sure that equipment is working!* For example, when security guards make their rounds, have them check the buttons for the accessible doors.

5. Environment

People with disabilities sometimes have sensitivities to light, temperature, chemicals, and other aspects of their surroundings and may require some accommodations to meet their needs.

- Use cleaning solutions that will not cause allergic or respiratory reactions.
- Be willing to adjust lighting. Florescent lights may need to be turned off for people with seizure disorder, and alternate light sources should be available. Also lighting specialists are available to create the best lighting possible for people with vision issues.
- People with disabilities often have more difficulty with temperature tolerance. Please be sensitive to these needs.
- If someone has a support animal, this animal should be allowed to support the individual within the facility.
- Sometimes a person may be too ill or uncomfortable to ask for an accommodation. Staff should use common courtesy to assist individuals with disabilities.

Diet and eating:

- People who cannot use the phone or understand the menu should be offered assistance.
- Some individuals cannot feed themselves. Staff need to assess the individual's ability to feed themselves, and be available to provide assistance if needed.

- Ensure that individuals with special dietary requirements (such as low sugar or salt) get those needs met.

6. Architectural

Most health care providers and staff are familiar with the legal requirements set forth under the Americans with Disabilities Act (ADA). However, the ADA standards are minimum requirements for very basic accessibility. When remodeling or undertaking new construction, health care providers have an opportunity to increase accessibility beyond the minimum ADA requirements, and create an architectural environment that is more friendly and accessible to people with disabilities, people with illnesses, injuries and medical conditions (including pregnancy!) that result in limited mobility, and elderly patients (a growing population as our the percent of elderly in our nation is on the increase).

- Restrooms in all areas, including patient rooms and staff areas, need to be wheelchair accessible.
- All reception and food service counters should have a lower area for people using wheelchairs or for people who are of short stature. Keep these areas clear of displays and computers, because they are for patients to use.
- Exam rooms should be large enough to fit people in wheelchairs (without the door hitting the wheelchair), whether they are the patient or the support person for the patient.
- Health care providers need to have enough accessible parking to accommodate demand. As more elderly people get permits, the demand with continue to increase.
- Avoid carpet and carpet pads that are difficult to push a wheelchair on.
- If there are steps, ramps need to be located right next to the steps. People who cannot use steps should be able to easily get to all places.
- Power doors should be installed at the most frequently used doors to assist all patients.
- Qualified persons with various disabilities should be consulted when changes are being made to the structure of the facility.

7. Common Areas

- In waiting areas, there should be spaces where people in wheelchairs can sit with other people who are waiting.

- Turn on the closed captioning feature on the televisions in waiting areas.
- Have chairs with and without armrests, or chairs that accommodate larger people. Larger people feel uncomfortable with armrests on smaller chairs, and others need armrests to stand or transfer.

8. Staff Training: Tips for Managers and Trainers

This section of the handout consists of tips and advice for health care provider personnel who are in charge of training other staff, or developing the training curriculum. Medical personnel – whether doctors or nurses or techs – get very little, if any formal training on working with people with disabilities. Non-medical staff, such as housekeeping and administrative staff, may get no training at all, even though their jobs may require them to interact with patients or the public.

- All levels of staff that may come in contact with patients or their families (security, information desk, housekeeping, nurses, doctors, etc.) need to be educated and trained on communicating with people with various disabilities.
- People with disabilities often know a great deal about their condition. It is important to value and not dismiss this knowledge. Train staff to communicate with the patient regarding different treatment options and the patient's experience with them.
- Encourage staff to understand that disability is not an illness. Too frequently the "medical model" gives the impression that a disability is an illness and that a person with a disability is to be treated as a "sick" person. This is alienating to the person with the disability.
- Learn to be sensitive to the individual's needs and abilities. Do not ask a person in a wheelchair to stand. Conversely, do not assume they cannot. Staff should be trained to *ask* the person in the wheelchair **if** they **can** stand.
- Staff should never be rude to patients, even if the staff become frustrated. Although some people with disabilities may be difficult (perhaps because of the disabling condition, or simply because of personality), staff should be trained to deal with difficulties in a professional manner. Rude behavior is not acceptable.
- Teach staff that sometimes insurance companies will pay for treatments or equipment for people with disabilities, when they would not do the same for people without disabilities. Staff should pursue these options when appropriate for the patient.
- Staff should be trained to be aware of what would make the experience easier for patients. For example, if a person in a wheelchair is in an exam room, make sure he/she will not be hit by a door. Remove extra chairs if necessary.
- In order for sensitivity or disability awareness training to have maximum impact, qualified people with disabilities should be involved in the training. Staff will better

understand the points when they hear the information directly from someone who is affected.

- Allow staff to be creative and flexible in solving problems. Help them to seek solutions that work best for everyone. For example, if a person is not able to transfer to a table because it is too high, staff can bring in ramps. If a patient is anxious about walking through a waiting room, staff can have him/her enter through a side door.

Conclusion

The CCHCC Disability Rights Task Force hopes that this handout has been helpful to you. Ultimately, the vision for health care for people with disabilities is the same as for people without disabilities – we all want patient-centered care. Creating greater accessibility by removing structural barriers, and creating better communication by practicing basic etiquette, listening and valuing the patient's experience, and treating all patients *as people*, are key components of providing patient-centered care for all people, including people with disabilities. We know that we, as people with disabilities, share the same health care goals as our health care providers – the highest quality health care possible to achieve the healthiest outcome. Thank you for taking the time to read this handout.

This information was compiled by: The *Disability Rights Task Force* (DRTF).
DRTF is a group led by people with disabilities, dedicated to working with health care providers to improve health care accessibility and services for patients with disabilities.

DRTF is a task force of Champaign County Health Care Consumers (CCHCC), a citizen action organization working to create meaningful reforms in the health care system through the active involvement of consumers.

For more information, please contact CCHCC:
44 E. Main Street, Suite 208, Champaign, IL 61820
(217) 352-6533 • cchcc@healthcareconsumers.org • www.healthcareconsumers.org