

# Making Preventive Health Care Work for You

## *A Resource Guide for People with Physical Disabilities*

Edition 2.0



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Kailes, June Isaacson. *Making Preventive Health Care Work for You – A Resource Guide for People with Physical Disabilities*, 2006. The Center for Disability Issues and the Health Professions, Western University of Health Sciences, 309 E. Second Street, Pomona, CA 91766-1854, voice/TTY 1-800-832-0524, e-mail [ahcs@westernu.edu](mailto:ahcs@westernu.edu), [www.cdihp.org](http://www.cdihp.org)

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# Making Preventive Health Care Work for You

## *A Resource Guide for People with Physical Disabilities*

Edition 2.0



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## Acknowledgements

Project SHIELD (Strategies and Health Interventions to Enhance Life with Disability) works to improve and protect the health of adults with physical disabilities. *Making Preventive Health Care Work for You – A Resource Guide for People with Physical Disabilities* was developed by the Project SHIELD team. It is designed for use by people with physical disabilities and their health care providers to improve access to preventive screenings that are essential to the health and well-being of every person.

When using this Guide, you should always consult with your health care providers before undertaking any recommended treatment interventions. You should also direct questions about your medical conditions to your health care providers.

The following organizations worked together to create this Resource Guide:

- ◆ Center for Health & Disability Research, National Rehabilitation Hospital, Washington, D.C.
- ◆ ENDependence Center of Northern Virginia, Arlington, Virginia
- ◆ Center for Disability Issues and the Health Professions, Western University of Health Sciences, Pomona, California
- ◆ DisabilityGuide.org, Boyds, Maryland

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This Resource Guide was developed with grant #R04/CCR323280 from the Centers for Disease Control and Prevention (CDC), awarded to the Center for Health & Disability Research, National Rehabilitation Hospital, Washington, D.C. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the CDC.

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The creator of this Resource Guide acknowledges and thanks:

- ◆ Project SHIELD’s Community Steering Committee – Janet Dorsey, Maya Flores, Tom Kelley, April Myers, and Bob Sevigny – for providing critical consumer input.
- ◆ Michael Cooper, Salley Michael, Marcie Goldstein, and the team at ECNV for their leadership and support of Project SHIELD and for their work with the Community Steering Committee.
- ◆ These individuals for their highly valued wisdom, time, effort, insightful content suggestions, and diligent editing contributions for various drafts of this Resource Guide:
  - Gwyn C. Jones, PhD, Project Director/Principal Investigator
  - Thilo Kroll, PhD, Co-Principal Investigator
  - Melinda T. Neri, BA, Research Associate
  - Matthew E. Kehn, BA, Research Assistant
  - Suzanne L. Groah, MD, MSPH, Medical Consultant
  - Tom Kelley, Steering Committee Member

## **We Welcome Your Comments**

The Center for Disability Issues and the Health Professions staff invites your feedback about our resource materials. We would appreciate it if you would take a few minutes to complete and return the feedback form found at the back of this Resource Guide. We welcome your comments.

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## Part 1

# Using This Guide

### Key Terms Often Used in This Guide

**HEALTH CARE PROVIDER** or **PROVIDER** refers to a broad group of people and organizations who provide health services. Providers include doctors, nurses, therapists, social workers, hospitals, and other health care professionals.

**IMMUNIZATIONS** (also called **VACCINES** or shots), can protect you against serious diseases, like the flu or pneumonia.

**LIFESTYLE** includes your diet and eating habits, the amount of exercise or physical activity you get, whether you smoke cigarettes or use other forms of tobacco, how much and how often you drink alcohol, whether you use marijuana, cocaine, or other drugs, whether you take steps to prevent sexually transmitted diseases (STDs) and your use of contraceptives (birth control).

**PRIMARY CARE DOCTOR** is your main doctor, who is usually who you go to first when you are sick or need advice about your health.

**ROUTINE HEALTH SCREENING** is done to assess your general health and to look for signs of health problems. Your primary care doctor should do a routine health screening when doing a physical exam. These screenings are sometimes called **PREVENTIVE HEALTH SCREENINGS** or check-ups.

This Guide recognizes that when you live with a disability:

- ◆ It is not always easy to get the preventive health service you need
- ◆ Getting the health care you need takes work

- ◆ When you're active in your health care, you get better results

People with disabilities often don't get the kinds of preventive health services they need. As an individual with a disability, you often have to deal with more barriers



## The Resource Guide can help you:

- ◆ Learn what health risks you may have
- ◆ Learn why routine preventive screenings and vaccines are important
- ◆ Create a Routine Screening and Immunization Plan tailored to your own needs
- ◆ Learn how to be more active in your health care
- ◆ Increase your confidence when working with health care providers
- ◆ Improve your communication with health care providers
- ◆ Get the disability specific help you may need

than people without disabilities. For example, you might put off getting medical checkups because it's hard to get to the doctor's office. You might also avoid checkups because the office staff are not willing to help with your needs. Because of these and other disability specific access issues, this Guide covers:

- ◆ How to take steps to make preventive health care work for you

- ◆ How to be active in planning for and communicating your needs

Both of these areas are important, because unlike a person without a disability, it is important that you understand what routine screening you need and that you have the skills to get it. For example, the center you have been referred to to get a mammogram tells you that their equipment is not usable by you because you cannot stand up. Do you give up? Do you ask your provider to check the access and usability of other facilities before they give you a referral?

Good health is possible for most people with disabilities. Even with a disability, activity limitations, or chronic conditions, you can live a healthy life. You can also deal with stress, and function well in everyday life—and that is the meaning of good health.

Understanding your risk of developing health problems is a first step toward good health. Getting high-quality preventive care is also an important part of staying healthy. Regular checkups can detect signs of problems like diabetes, cancer, or heart disease early enough to be treated. During checkups, your health care providers can also suggest ways to make lifestyle changes. These changes may help you to become healthier and prevent future problems.

This Guide was not written to be read and then put on a shelf. Rather, it offers information and tools to help you assess your situation and get the most from preventive health care visits. Many of the tools can be used over and over when you go to the doctor. They can also be used when your health needs change.

You can use this Resource Guide in a way that works best for you. For a thorough view of health risks, routine screenings, and disability-related issues, read it cover to cover. If you don't have time to read the entire Guide now, start with reading the sections that you want to know more

about and the skills you want to strengthen.

You can also use the Guide when you're ready to go to the doctor or if you have a specific need or question. Extra copies of the tools and checklists are found in Part 6 of the Guide as well as at [www.CDIHP.org](http://www.CDIHP.org) (click on products).

After using this Resource Guide, you should be able to take a more active role in your health care. As a result, you will be better prepared to work in partnership with your health care providers to get the preventive services you need.

## **Beliefs and Ideas to Help Guide You**

There are many ideas and suggestions in this Guide. If you try to believe in these ideas and suggestions, you will benefit more from this booklet. While you read the following pages, you should keep in mind that:

- You can have a positive affect on your health.
- You can have a disability and still be healthy.
- You may need to work to get the health care that you need.
- You will get better results with your health care when you play an active role in it.
- You have the responsibility and the right to speak up about your health care. If you don't speak up, you may not get important care.
- You should form relationships with health care providers that are like partnerships.

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## Tools and Tables at a Glance

### Part 1: Using This Guide

Ways to Make Preventive Health Care Work for You	This table lists important goals and activities described in more detail throughout the Resource Guide.	Page 13
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### Part 2: Your Health Risks

My Risk Factors Checklist	Use this checklist to assess your personal risk factors for selected diseases and conditions.	Page 19
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### Part 3: Routine Health Screening

Recommended Routine Health Screenings	This table lists many important health screenings and tells why and when you should have them.	Page 26
Recommended Vaccines	This table lists important vaccines and states when to get them, how often to get them and who should have them.	Page 29
Routine Screening and Immunization Plan	Use this tool for planning and as a record of your routine preventive health screenings and immunizations.	Page 32

### Part 4: Become an Active Health Care Consumer

Are You an Active or Passive Health Care Consumer?	This tool helps you decide whether you are active or passive when working with health care providers.	Page 38
Health Care Visit Strategies Quiz	Take this quiz to see if you make the best use of very limited time during your visits with a health provider.	Page 39

## Part 4: Become an Active Health Care Consumer (continued)

Checklist for Planning Ahead If You Need Disability-Specific Assistance	Use this tool to determine your disability-related needs that should be addressed before visiting your doctor or other health care providers.	Page 41
Types of Communication	This table gives examples of different types of communication styles that are either not helpful or helpful when working with health care providers.	Page 44
The DES Script	Use this tool to sharpen your communication skills.	Page 45
Test Result Communication Form	Use this form to help ensure that you and your other providers get copies of your test results.	Page 51

## Part 5: Resources

More About Routine Screening Tests	This table lists screening tests for many diseases and conditions and briefly describes how they help.	Page 53
More About Vaccines	This table lists vaccines for many diseases and summarizes how they help.	Page 57
Quiz - How Much Do You Know About Routine Screenings?	Direct your reading to specific sections based on skills you want to strengthen.	Page 59
Organizations and Web Sites	Contact the organizations listed or visit their Web sites to gather useful information.	Page 61
Routine Preventive Screening for People with Physical Disabilities: Tips for Health Care Providers	Give this tool to your health care professionals to inform them about routine screening for people with physical disabilities.	Page 65

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My Risk Factors Checklist	<p><b>Extra copies for you to tear out, use and copy.</b></p>
Routine Screening and Immunization Plan	
Checklist for Planning Ahead If You Need Disability- Specific Assistance	
Test Result Communication Form	
Routine Preventive Screening for People with Physical Disabilities: Tips for Health Care Providers	

**Guide Feedback Form**

Guide Feedback Form	Please tell us what you think about this Guide.	Page 109
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## Ways to Make Preventive Health Screening Work for You

Goal	What You Can Do	To learn more, read this part of the Resource Guide
Develop beliefs	Recognize that: <ul style="list-style-type: none"> <li>You can have a disability and be healthy</li> <li>You can positively affect your health</li> <li>Get routine screenings to stay healthy and productive</li> <li>You will get better results with your health care if you are active in your relationships with your doctors</li> </ul>	Part 1: Using this Guide Part 2: Your Health Risks
Develop knowledge	<ul style="list-style-type: none"> <li>Know your risk factors</li> <li>Know the importance of routine screenings and vaccines and what they involve</li> </ul>	Part 2: Your Health Risks Part 3: Routine Health Screening Part 5: Resources
Know your risk factors	<ul style="list-style-type: none"> <li>Learn about the importance of family, lifestyle, and disability-specific risk factors</li> <li>Complete the “My Risk Factors” checklist</li> </ul>	Part 2: Your Health Risks
Make a plan	<ul style="list-style-type: none"> <li>Create your Routine Screening and Immunization Plan</li> </ul>	Part 3: Routine Health Screening
Practice skills	<ul style="list-style-type: none"> <li>Practice skills to help you be active in your health care</li> <li>Practice skills to help you deal with access barriers</li> </ul>	Part 4: Become an Active Health Care Consumer
Follow your plan	<ul style="list-style-type: none"> <li>Discuss your Routine Screening and Immunization Plan with your doctor</li> <li>Make changes to your plan, based on this discussion</li> <li>Follow your plan by getting the checkups, tests, and shots you need</li> </ul>	Part 3: Routine Health Screening Part 4: Become an Active Health Care Consumer Part 5: Resources
Follow up	<ul style="list-style-type: none"> <li>Get the results of your procedures and tests</li> </ul>	Part 4: Become an Active Health Care Consumer
Update your plan	<ul style="list-style-type: none"> <li>Update your plan</li> </ul>	Part 3: Routine Health Screening Part 4: Become an Active Health Care Consumer

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## Notes

## Part 2

# Your Health Risks

If you have a limited ability or no ability to walk, do not exercise regularly, and have an inactive lifestyle, your risk of other health problems will increase. This makes it even more important for you to get the right routine health screenings at the right time. You should ask your doctor about a weight-control and exercise program that could work for you. If your doctor does not know what to tell you, ask for referrals. A nutritionist can help you with your diet. A physical or occupational therapist who understands your disability can create an exercise program for you.

## Can You Have a Disability and Still Be Healthy?

Good health is possible for most people with disabilities. It also is something you can positively affect. “Health” means being able to make the most of your physical, social, emotional, spiritual, and intellectual abilities. It is important to view health as being able to function well, to meet your needs, and to adapt to stresses. You can live a healthy life even if you have a disability or chronic condition.

If you have a disability, it’s important to reject the common belief that good health is beyond your reach. Get rid of the belief that decline, illness, and conditions related to your disability (sometimes referred to as



secondary conditions) or unrelated to your disability are certain for you. Although this thinking is common, it is based on disability myths, fears, and stereotypes.



**“Learned helplessness truly is the greatestcrippler anyone can experience. And, many people with disabilities have unfortunately learned to be passive, if not completely disengaged, where questions of their own health and well being are concerned. Many see health as just one more thing beyond their control, something they cannot change or influence.”**

**Bob Williams, Disability Advocate**

These myths, fears, and stereotypes can affect the quality of health care services you get.

Explore whether these beliefs and low expectations have crept into your thoughts and attitudes about your ability to be healthy. If they have, work at erasing them.

## **How Can You Increase Your Odds for a Healthy Life?**

You can take steps to increase your odds of living a healthy and long life. Checkups and tests can help find problems early, when they are easier to treat. For example, heart disease is a major killer in this country. To help prevent heart disease, it is useful to know what your risk factors are

and to take steps to reduce your risks. It is also important to have routine preventive screenings that can detect signs of heart disease. These screenings include blood pressure and cholesterol checks.

Finding health problems early and making healthy lifestyle changes may save or lengthen your life! Vaccines can help prevent serious diseases, too. Your doctor may also suggest medicines or procedures to help prevent or slow the progress of some health problems. Knowing the facts and talking with your health care providers about them can improve your chances of getting the services you need.

## **What Are Your Risk Factors?**

Your family history, lifestyle, and disability may mean that you are at risk for certain health problems. This may mean you need to get certain routine health screenings sooner than other people do. It may also mean you need to get screened more often than other people.

Knowing your health risks can help you decide what preventive screenings you need and when you need them. Higher risks mean you may need to be screened at an earlier age and more often than usual. Use the “My Risk Factors Checklist” below to assess your health risks. Share the list with your health care provider during checkups.

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## Family History Risk Factors

Some health conditions may be a part of your family history. For example, your family may have a history of heart disease, cancer, or diabetes. This increases your risk of getting these diseases.

Knowing about your family's medical history can have life-saving value. It can also be an important piece of information that you give your children. Tell your doctors what you know about your family health history. Work with them to be sure you get routine health screenings that may be able to detect and treat inherited conditions early.

## Lifestyle Risk Factors

Your lifestyle can affect your health. For instance, an unhealthy diet, lack of physical activity, smoking, drinking too much alcohol, and not taking steps to prevent sexually transmitted diseases can increase your chances of poor health.

Even if you have a disability, it is important to avoid such risks and to make healthy lifestyle choices. These choices may be even more important for you than for others. Making lifestyle changes can help prevent future problems.

## Disability-Related Risk Factors

Limited or no ability to walk, lack of regular exercise, and a more inactive lifestyle can raise your risk for some health

problems. These problems include diabetes, osteoporosis, heart disease, and some cancers. Studies also show that people with limited mobility (for example, people with spinal cord injury, cerebral palsy, and post-polio syndrome) can



experience certain conditions earlier than people of the same age who do not have disabilities.

These facts make it even more important for you to get the right routine health screenings at the right time. They also mean that you should ask your doctor about a weight-control and exercise program that could work for you. If your doctor does not know what to tell you, ask for some referrals. A nutritionist can help you with your diet. A physical or occupational therapist who understands your disability can help you with an exercise program.

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## The Importance of Knowing Your Risk Factors

Knowing your health risks can help you decide what preventive screenings you need and when you need them. For example:

- Maria's mother and sister had breast cancer. Because of her family history, she began getting a yearly mammogram at age 35, rather than waiting until the recommended age of 50.
- Li's father and grandfather had prostate cancer at an early age. Li began getting screening tests every year for prostate cancer at age 40 instead of age 50.
- Terry's parents both had colon cancer so she began getting screened at age 30.
- Chin has two sisters who had cervical cancer. She gets a Pap smear every year.
- Larry, age 25, a wheelchair user due to spinal cord injury since age 18, had his bone density checked prior to starting a new exercise program.

See **Part 3** to learn about routine health screenings.



## My Risk Factors Checklist

Use this checklist to assess your health risks. Check any item that applies to you, and then share the list with your health care providers. Together, you can create and follow a Routine Screening and Immunization Plan tailored to your needs (see Part 3 of this Guide).

### Breast Cancer

Over age 50 (The chance of getting breast cancer goes up as a woman gets older; 80% of breast cancers occur in women over 50.)

Personal history of breast cancer (A woman who has had breast cancer in one breast has an increased risk of getting this disease in her other breast.)

Family history of breast cancer (especially in your mother, sister, or daughter) (The more relatives you have who got breast cancer before menopause the greater your risk)

History of breast biopsy with atypical (not normal) findings

Family or personal history of gene abnormalities related to breast cancer (Women who are of Eastern and Central European Jewish ancestry are at risk.)

No pregnancies or first pregnancy after age 35

Early onset of menstruation (before age 12)

Late menopause (after age 55)

White (Breast cancer occurs more often in white women than Latina, Asian, or African-American women.)

Overweight /obese

Use of hormone therapy consisting of estrogen plus progestin

Female (Men can develop breast cancer, but it is 100 times more common in women.)

### Cervical Cancer

History of cervical cancer or a pre-cancerous Pap test

History of a sexually transmitted disease

Family history of cervical cancer

Multiple sexual partners

Sexual activity before age 18

A partner who began sexual activity at an early age or who had many previous sexual partners

Infection with human papillomavirus (HPV, the virus that causes genital warts)

Smoking

Exposure to diethylstilbestrol (DES) before birth



## My Risk Factors Checklist (continued)

### Cervical Cancer (continued)

HIV infection

Weakened immune system due to such factors as an organ transplant, chemotherapy, or chronic corticosteroid use

### Colon and Rectal Cancer

History of colorectal cancer or adenomatous polyps (growths that project, usually on a stalk, from the lining of the colon or rectum)

History of inflammatory bowel disease such as Crohn's disease or ulcerative colitis

Family history of colorectal cancer or adenomatous polyps

Evidence of genetic colorectal cancer syndrome

High-fat, low-fiber diet

Smoking

Inactivity/lack of exercise

Extremely overweight (obese)

Diabetes

Heavy alcohol use

Eastern European Jewish descent (particularly Ashkenazi Jews)

### Diabetes

Family history of diabetes (in parents, brothers, or sisters)

Inactivity/lack of exercise

Overweight

Over age 45 (The risk of type 2 diabetes rises with age, especially after age 45.)

African American, American Indian, or Hispanic

### Obesity

Diet of high-calorie foods, such as fast foods, soft drinks, and sweets

Inactivity/lack of exercise

Family history of obesity (in parents)

Overeating to cope with problems or deal with difficult emotions

Use of certain medications (Corticosteroids and tricyclic antidepressants, in particular, can lead to weight gain.)

A medical condition that leads to decreased activity



## My Risk Factors Checklist (continued)

### Osteoporosis

Being a white or Asian woman

Family history of osteoporosis

Early menopause (may occur because of early failure of the ovaries, surgical removal of a woman's ovaries, or chemotherapy for cancer)

Had surgery to remove ovaries

Had extended bed rest

Inactivity/lack of exercise

Extended use of certain medicines (such as prednisone, cortisone, prednisolone, and dexamethasone)

Small body frame/very thin

Smoking

Heavy alcohol use

Eating disorder (anorexia nervosa or bulimia)

### Prostate Cancer

Male over age 50

African-American male (Prostate cancer occurs almost 70 percent more often in black men than it does in white men.)

Family history (in father or brother)

High-fat diet

Overweight

### High Cholesterol

Inactivity/lack of exercise

Overweight

High-fat, high-cholesterol diet

Smoking

Type 2 diabetes

Family history of atherosclerosis (narrowing of the arteries)

High blood pressure



## My Risk Factors Checklist (continued)

### High Blood Pressure

	Inactivity, lack of exercise
	Family history
	Age (90% of people who, at age 55, do not have hypertension will eventually develop it.)
	African American
	Heavy alcohol use
	Low intake of potassium, magnesium, and calcium
	Overweight/obese
	Smoking
	High sodium (salt) intake
	Sodium/salt sensitivity (People who are sodium sensitive retain sodium. This can lead to fluid retention and high blood pressure.)
	Low potassium intake
	High levels of stress can lead to temporary but striking increase in blood pressure.
	High blood cholesterol
	Diabetes
	Sleep apnea (breathing stops for short periods of time during sleep.)

### Important Ideas to Remember

- If you have a disability, you can still get cancer, diabetes, high blood pressure, high cholesterol, and other health problems.
- Some people with physical disabilities have more health risks than most people. You may have a greater risk for some preventable health conditions, like high blood pressure, diabetes, and low bone density.
- If someone in your family has a certain condition, you may be more likely to get it. Also your lifestyle could contribute to you being more likely to get a certain condition. This means that you may need to get certain tests, or screenings, earlier or more often than other people do.
- The healthier you are, the more independent you can be. You'll also be able to do what you want to or need to do and be able to enjoy life.

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## Part 3

# Routine Health Screening

If your doctor or nurse doesn't talk about issues that you are concerned about, bring up the issues yourself. Your concerns might include being overweight, birth control, smoking, drug use, heavy alcohol use, or prevention of sexually transmitted diseases, for example. Explain that these issues are as important to you as they are to people who don't have disabilities.

## What is Routine Health Screening?

Routine health screening is done to assess your general health and to look for signs of health problems. Your primary care doctor (the doctor you usually go to first when you are sick or need advice about your health) should do a routine health screening when doing a physical exam. These screenings are sometimes called preventive health screenings or check-ups. They include:

- ◆ Checkups and tests (for example to

check your weight, blood pressure, cholesterol levels, and to look for signs of cancer and heart disease)

- ◆ Immunizations (also called vaccines or shots) such as those for flu and pneumonia
- ◆ Assessment of health risks and healthy lifestyle counseling about:
  - the importance of regular exercise
  - diet and eating habits
  - smoking
  - drug use
  - heavy alcohol use
  - birth control
  - sexually transmitted diseases

Several national health groups and government agencies make recommendations about which preventive tests and vaccines a person should have and when to get them. Sometimes these recommendations are not consistent. They also may change over time. Be sure to talk with your doctor about which screenings and vaccines are right for you.



## Will Your Doctor Tell You What You Need?

Some people compare today's physical exam to a pit stop: check cholesterol, check blood pressure, and you're done! When you visit doctors, don't assume that they will take care of all your routine screenings. Be sure to understand your



health and wellness needs and ask for what you think should be done. Your health care providers may not fully understand your disability-related health risks and needs.

Also, keep in mind that having a disability will not protect you from cancer, diabetes, high blood pressure, or high cholesterol. People with disabilities have to be concerned about the same health risks as everyone else. People with disabilities also

need to be aware of specific risks that may be associated with their disability.

## Why is Routine Screening Especially Important for People with Disabilities?

Some people with physical disabilities have greater health risks than the general population. Because of physical limitations and other factors, they may be more at risk for preventable health conditions, such as high blood pressure, diabetes, and osteoporosis.

However, people with disabilities often face barriers to getting routine screening. The reasons for this include:

- ◆ People with disabilities may face physical barriers related to:
  - transportation (not having accessible, reliable, and safe services to and from the provider's office)
  - building access (lack of ramps and usable doors, bathrooms, and exam rooms)
  - equipment accessibility (lack of height-adjustable exam tables, accessible scales, and inaccessible machines for mammograms and bone-density tests)
- ◆ The health care provider's office staff may not be trained or available to help

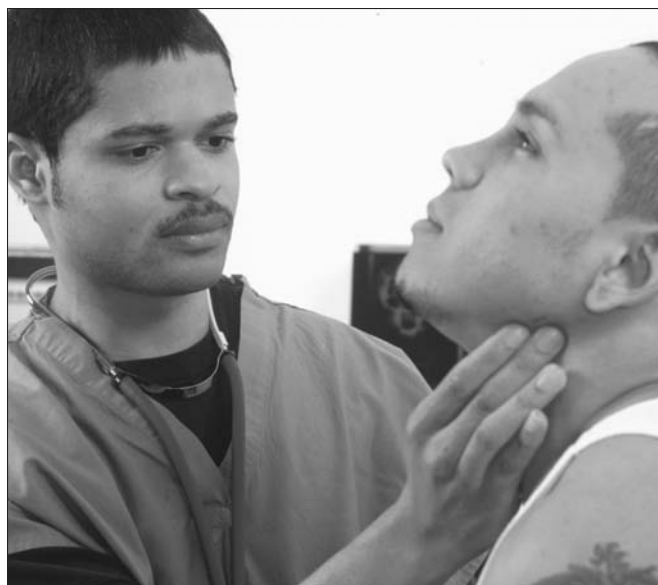
with safe wheelchair transfers and positioning.

- ◆ Many health care providers lack disability-specific experience or think that all health problems are caused by the person's disability.
- ◆ Health care providers often do not address general, sexual, diet, and exercise issues because they focus only on the disabling condition.

As a result, people with disabilities often have lower use rates of routine screening when compared to the general population.

## Why Are Checkups Important?

Many people avoid going to health care providers and getting routine preventive checkups. They put off doctor visits because they're too much trouble or they fear bad news. People with disabilities have other reasons for not getting routine care, too. You may feel frustrated, angry or embarrassed because of a lack of access or available assistance. You may also have experienced providers who did not respect you, were not sensitive toward you, or didn't understand your disability. In addition, you may have found that arranging for transportation and accessible providers who can meet your needs takes a lot of time and physical and emotional energy.



Whatever your reasons, avoiding health care visits is not a good idea. In fact, putting off doctor visits can have a negative impact on your health. Many conditions can be successfully treated if found early. You can also work to make lifestyle changes if you know you are at risk for heart disease, osteoporosis, or other health problems.

Take advantage of your physical exam time to talk with your doctor about your health. Educate him or her about your disability. This helps you build a partnership with the doctor. Having a good working relationship is helpful in case something is found.

The table below lists many recommended routine health screenings that you should receive. The tools found in Part 4 of this Guide can help you to deal with some of the health care barriers you may experience as a person with a disability.

## Recommended Routine Health Screenings

No single screening schedule is right for everyone. Use this table as a guide. Determine your risk factors, and then work with your doctor to plan for a schedule that is right for you.

Screening	Why You Should Have It	When to Have the Screening (If You Have No Known Risk Factors)
<b>Screenings for Everyone</b>		
Physical exam	To assess your overall physical health	Yearly
Blood pressure check	To measure the pressure of your blood against the walls of your blood vessels, especially the arteries  The longer high blood pressure goes untreated, the higher your risk of heart attack, stroke, heart failure, and kidney damage.	Yearly
Weight check	To screen for overweight, obesity, or unusual weight loss.  A change in weight can be a risk factor for or a sign of diabetes, heart disease, kidney disease, or cancer.	Each visit
Cholesterol check	To measure your cholesterol levels.  Too much cholesterol in blood can lead to hardening of the arteries, which can cause heart attack, stroke, and/or severe pain with walking. Cholesterol includes high-density lipoproteins (HDL, the “good” type cholesterol), and low-density lipoproteins (LDL, the “bad” type of cholesterol).	Have a baseline test in your 20s, and then at least every 5 years.
Bone-density test	To assess your risk of osteoporosis (porous, brittle bones).	<ul style="list-style-type: none"> <li>• Women aged 65 and older should be screened routinely for osteoporosis.</li> <li>• Screening at age 60 for women at increased risk.</li> <li>• Consider your risk factors, then discuss your risk with your doctor and make a plan.</li> </ul>

## Recommended Routine Health Screenings (continued)

Screening	Why You Should Have It	When to Have the Screening (If You Have No Known Risk Factors)
<b>Screenings for Everyone (continued)</b>		
Colorectal cancer tests	To detect colon polyps that may become cancerous or colon cancers before symptoms occur.	Talk with your doctor about which of the following recommendations are right for you: <ul style="list-style-type: none"> <li>• Yearly fecal occult blood test (FOBT)</li> <li>• Yearly FOBT plus flexible sigmoidoscopy every 5 years</li> <li>• Flexible sigmoidoscopy every 5 years</li> <li>• Double-contrast barium enema every 5 years</li> <li>• Colonoscopy every 10 years</li> </ul>
Blood sugar (glucose) test	To determine if your body is having problems using blood sugar (glucose) and if you are at risk for having diabetes.	Measurement of blood sugar starting at age 45, with repeated tests done every 3 years.
<b>Screenings for Women Only</b>		
Mammogram	To test for signs of breast cancer/tumors.	Starting at age 40, with repeat tests every 1-2 years
Clinical breast exam	To check for signs of breast cancer/tumors.	Age 20-39: Every 3 years Age 40 and older: Yearly
Breast self-exam	To check for lumps in the breast.	Age 20 and older: Monthly
Pap test (done with pelvic exam)	To detect signs of cervical cancer, infection, or other problems.	First Pap test within 2 years after first having sexual relations or at age 21 if you have not been sexually active  Age 21-29: Every 1-2 years  Age 30-69: Every 2 to 3 years if you have had 3 normal Pap tests in a row  Age 70 and older: You may stop having Pap tests if you've had 3 normal Pap tests in a row and you have had normal Pap tests in the past 10 years.

## Recommended Routine Health Screenings (continued)

Screening	Why You Should Have It	When to Have the Screening (If You Have No Known Risk Factors)
<b>Screenings for Men Only</b>		
Digital rectal exam	To detect prostate cancer.	Discuss with your health care provider
Prostate-specific antigen (PSA) test	To detect prostate cancer.	Discuss with your health care provider

Sources: American Cancer Society; American Heart Association; Mayo Clinic; and Multisociety Task Force on Colorectal Cancer (a consortium that includes the American College of Gastroenterology, the American College of Physicians, the American Gastroenterological Association, and the American Society for Gastrointestinal Endoscopy).

## What about Vaccines?

Vaccines, also called immunizations or shots, are not just for children! Adults also need to be vaccinated to protect themselves against serious infectious diseases. Some shots are actually more important for adults than for children.

Vaccines help protect you from diseases. They cause your immune system to develop antibodies. The antibodies can recognize and attack the organism if you are exposed to it. An immunization does not always prevent the disease, but it can reduce the disease's severity and



symptoms. Vaccines can also save lives. For example, the flu usually is a mild disease. However, it can be life-threatening in older adults and people

with chronic respiratory conditions and other risk factors.

Some recommended vaccines are listed in the table below. It's helpful to keep a personal immunization record with the types and dates of shots you've received, as well as any side effects or problems you experienced after getting

the shot. Use the Routine Screening and Immunization Plan below to keep a record of the shots you have had.

## Recommended Vaccines

Vaccine	When to Get It	How Often to Get It	Who Should Have It
Influenza (flu)	Six to 23 months; over age 50	Yearly, between September and November before flu season starts; you may also get the vaccine throughout the flu season	<p>People who:</p> <ul style="list-style-type: none"> <li>• Have asthma, diabetes or heart, lung, or kidney disease, or compromised immunity</li> <li>• Are health care workers</li> <li>• Live in a long-term care facility, such as a nursing home</li> <li>• Require close medical follow-up or have been in a hospital during the past year because of a serious disease, such as diabetes, lung, heart, or kidney condition, or HIV infection</li> <li>• Are taking medications that suppress the immune system</li> <li>• Will be more than 3 months pregnant during the flu season. (Flu vaccine is safe for pregnant women and safe for babies to breastfeed after their mothers have had flu shot.)</li> <li>• Have conditions that put them at risk for complications due to the flu (such as spinal cord injury or respiratory conditions)</li> </ul>
Pneumonia/pneumococcal	Children under age 2; adults age 65 and older	<p>Once or twice</p> <p>You should have a second shot if:</p> <ul style="list-style-type: none"> <li>• You are 65 or older and got the shot more than 5 years ago</li> <li>• You were younger than 65 when you got the shot the first time</li> </ul> <p>No one should receive more than 2 shots</p>	<p>Anyone with chronic conditions that affect the:</p> <ul style="list-style-type: none"> <li>• Heart</li> <li>• Lungs</li> <li>• Kidney</li> <li>• Liver</li> </ul> <p>Anyone with:</p> <ul style="list-style-type: none"> <li>• Breathing difficulties</li> <li>• Diabetes</li> <li>• Sickle-cell anemia</li> <li>• Alcoholism</li> <li>• A weakened immune system</li> <li>• Spleen problems</li> </ul>
Measles, mumps, and rubella (MMR)	Everyone born during or after 1957 should receive at least one dose sometime after their first birthday	Some adults, such as health care workers and people who travel out of the United States, may need a second dose	People born before 1957 may be vaccinated if they believe they have never had one of these diseases. There is no harm in receiving the vaccine if you already are immune to the infection.

## Recommended Vaccines (continued)

Vaccine	When to Get It	How Often to Get It	Who Should Have It
Chickenpox (varicella)		Two doses for people 13 years and older	A vaccine is available to protect people who have not had chickenpox. However, people who have had chicken pox are naturally protected from getting it again.
Tetanus/diphtheria	Everyone	Every 10 years throughout life	<ul style="list-style-type: none"> <li>• Get a booster shot if you have a severe cut or puncture wound and have not had a booster in the past 5 to 10 years.</li> <li>• Most people get their first shot as children as a combined diphtheria-tetanus-pertussis (DTP) vaccine.</li> <li>• For adults, a combination shot, called a Td booster, protects against both tetanus and diphtheria.</li> </ul>
Polio (IPV or OPV)	Not usually recommended		<p>Not recommended for adults (age 18 and older) who live in the United States</p> <p>Recommended for:</p> <ul style="list-style-type: none"> <li>• Adults who travel to areas of the world where polio is common</li> <li>• Laboratory workers who might handle polio virus</li> <li>• Health care workers treating patients who could have polio</li> </ul>
Hepatitis A	2 years and older	2 doses within 12 months	<ul style="list-style-type: none"> <li>• People with chronic liver or clotting-factor conditions</li> <li>• People who abuse injection drugs</li> <li>• People who have multiple sex partners</li> <li>• Men who have sex with men</li> <li>• Travelers to countries that have high or intermediate outbreaks of hepatitis A</li> </ul>
Hepatitis B		3 doses over a period of 6 months; provides protection for at least 15 years	<ul style="list-style-type: none"> <li>• Health care workers</li> <li>• People who are on kidney dialysis</li> <li>• People who live with or have sex with carriers of hepatitis B</li> <li>• Men who have sex with men</li> <li>• People who abuse injection drugs</li> <li>• Inmates of correctional facilities</li> <li>• Travelers to countries with high or intermediate cases of chronic hepatitis B infection for more than 6 months</li> </ul>

Sources: American Cancer Society; American Heart Association; Mayo Clinic; and Multisociety Task Force on Colorectal Cancer (a consortium that includes the American College of Gastroenterology, the American College of Physicians, the American Gastroenterological Association, and the American Society for Gastrointestinal Endoscopy).

## What is Healthy Lifestyle Counseling?

Routine health screening should include an assessment of your health-related lifestyle. During checkups, your provider should provide healthy lifestyle counseling. The provider should ask you about:

- ◆ Your diet and eating habits
- ◆ The amount of exercise or physical activity you get
- ◆ Whether you smoke cigarettes or use other forms of tobacco
- ◆ How much and how often you drink alcohol
- ◆ Whether you use marijuana, cocaine, or other drugs
- ◆ Whether you take steps to prevent sexually transmitted diseases (for example, by using condoms)
- ◆ Your use of contraceptives (birth control)

Your doctor should also offer advice about making healthy lifestyle changes. If your doctor or nurse does not talk about issues that you are concerned about, bring up the issues yourself. Your concerns might include being overweight, birth control, smoking, drug use, heavy alcohol use, or prevention of sexually transmitted diseases, for example. Explain that these



issues are as important to you as they are to people who don't have disabilities.

Ask questions and expect answers. If you don't get them, it's OK to ask again.

## How Can You Create Your own Routine Screening and Immunization Plan?

When it comes to routine screenings, one size does not fit all. Now that you know about your personal health risks and routine preventive screenings, you can create a Routine Screening and Immunization Plan for yourself.

Use the Routine Screening and Immunization Plan on the next page to keep track of and plan for your screenings and shots. Make a copy to write on and keep this original for future use. Also, be sure to talk with your doctor and update or change it as needed.



## Routine Screening and Immunization Plan

	Completed	Next Due Date	Completed	Next Due Date
<b>Routine Preventive Screenings</b>				
Physical exam				
Blood pressure				
Height and weight				
Cholesterol check				
Colorectal cancer tests:				
Fecal occult blood test				
Flexible sigmoidoscopy				
Double-contrast barium enema				
Colonoscopy				
Bone-density test				
Blood sugar (glucose) test (for diabetes)				
<b>Immunizations</b>				
Flu				
Pneumonia/pneumococcal				
Tetanus/diphtheria				
Measles/mumps/rubella (MMR)				
Chickenpox				
Hepatitis A				
Hepatitis B				
<b>Women only!</b>				
Mammogram				
Clinical breast exam				
Pap test and pelvic exam				
<b>Men only!</b>				
Prostate cancer tests:				
Digital rectal exam				
Prostate specific antigen (PSA) test				
Urine test				

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## Important Ideas to Remember

- Many people tend to avoid routine screenings. This avoidance can have a negative impact on your health. Avoid avoidance!
- Don't assume that your doctor will take care of all your routine screenings. Ask for what you think you need.
- No single routine health screening schedule is right for everyone. Work with your doctor to develop a plan that is right for you.
- Healthy lifestyle counseling and vaccines can promote health and help prevent disease.

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## Notes

## Part 4

# Become an Active Health Care Consumer

Getting the most out of health care requires you to be active – not passive – in your health care. You are a customer who is purchasing services from your health care providers. You have a responsibility and a right to be involved in the decisions that affect you.

**Providers deserve respect, not worship! The old “doctor always knows best” attitude is outdated. You have to speak up or you may not get important care. Being passive can be dangerous to your health.**

Getting the preventive health care that you need, when you live with a disability is not always easy. People with disabilities often have to deal with more barriers than people without disabilities. Therefore, being active in getting the preventive health care can be even more important for you than for people without disabilities.

Being active in your health care includes:

- ◆ Treating your relationships with health care providers as partnerships

- ◆ Making the best use of very limited time with providers
- ◆ Planning ahead when you need disability-specific assistance
- ◆ Clearly communicating your needs to providers
- ◆ Understanding and remembering



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information from health care providers

- ◆ Getting your test results and making sure these results are shared with other health care providers active in your care.

## Why Is it Important to Have Good Relationships with Your Providers?

You need preventive care to maintain and protect your health, and you may need to get preventive care on a regular basis. Health care providers often do not understand the difficulties that people with disabilities have in getting their preventive care. You can help your provider understand your needs by sharing and working with him or her. Together, you can find ways to get the preventive care that you need.

Research tells us that people who are

**“Nobody can make you feel inferior without your consent.”**

– Eleanor Roosevelt

active in their relationships with their doctors get better results. People who communicate well with

doctors benefit medically and emotionally. They are physically healthier, recover faster, and are better able to deal with stress and pain.

It’s best to treat your relationships with your providers as partnerships and to choose providers who will do the same. Look for providers who:

- ◆ Welcome your active participation in health care decision making.
- ◆ Value open communication.
- ◆ Don’t feel threatened if you have a lot of knowledge about a health issue, even if they have very little or none.

## Should You Speak Up?

It’s been said that passive health care consumers are processed, instead of being partners in the process. That means that getting the most out of health care requires you to be active – not passive – in your health care. View yourself as a customer who is purchasing services from health care providers. You have a right and responsibility to be involved in the decisions that affect you. After all, your health and well-being are at stake.

Being active and speaking up does not mean you have to battle with your provider. You should be courteous, but you should also be truthful and assertive. This means knowing what you need and knowing what to ask for, being firm, and sometimes, being pushy. Bring your self-confidence, self-respect and self-advocacy skills with you. They are all important

when you are a co-manager and partner in your health care.

Here's an example: Fred is a wheelchair user, who, with help, can stand and walk a few steps. The first time Fred had a physical exam with a new doctor, the doctor never had him get out of his wheelchair. He assumed that Fred couldn't get up, and Fred felt too shy to suggest that the doctor do the exam differently. If Fred had explained that he could get out of his chair, he could have received a more complete physical exam.

A provider sees you only periodically, sometimes only once a year or less. You live in and with your body all the time. No one knows as much about your body's daily functioning as you do. Use this knowledge and understanding to boost your confidence.

Being prepared and having faith in your life experience and your common sense will help you avoid feeling anxious in health care situations. Knowing that you are a partner can help you feel comfortable about speaking up. Believe in and have confidence in your own experience. Don't be intimidated by credentials and degrees! You don't have to be a rocket scientist to be a partner in your health care. Your personal experience and knowledge are what count.

In addition, take steps to avoid being passive. When working with providers,



try to avoid:

- ◆ Wanting providers to take charge of your health
- ◆ Relying totally on providers' advice
- ◆ Failing to ask questions
- ◆ Offering information only when asked
- ◆ Adopting a “what will be will be” attitude
- ◆ Failing to think about options
- ◆ Feeling helpless and lost in the health care system
- ◆ Worrying that your health care will be negatively affected if you ask questions or disagree with a provider
- ◆ Being processed instead of being a partner in the process

Take the quiz on the next page to find out if you are an active or passive health care consumer. Then take the Health Care Strategy Quiz to find out how well you use your health care visit time.

## Are You an Active or Passive Health Care Consumer?

Answer Yes or No to the following questions to find out if you are an active or passive health care consumer.

Yes	No	
		1. Do you want health care providers to take charge?
		2. Do you find providers who will listen?
		3. Do you rely totally on the provider's advice?
		4. Do you find providers who will involve you fully in decisions?
		5. Do you avoid asking your providers questions?
		6. Do you try to learn as much as possible about your health conditions and continually seek updated information?
		7. Do you offer information only when asked?
		8. Do you ask questions and express concerns to your providers?
		9. Do you fail to think about your options?
		10. Do you view relationships with providers as partnerships?
		11. Do you feel helpless in the health care system?
		12. Do you share in decision making and responsibility for choosing health care options and alternatives?
		13. Do you share in decision making and responsibility for developing effective treatment plans?
		14. Do you share in decision making and responsibility for understanding your condition(s)?
		15. Do you share in decision making and responsibility for adopting practices that prevent or decrease complications?
		16. Do you share in decision making and responsibility for learning what your health plan covers?
		17. Do you worry that your health care will be negatively affected if you question, challenge, or disagree with a provider?
		18. Do you share in decisions to use community services and resources?
		19. Do you feel you are being "processed" instead of being a partner in the health care process?

### To Find Your Score

- ◆ If you answered YES to questions 2, 4, 6, 8, 10, 12-16, and 18: Congratulations! You have the characteristics of an active health care consumer. You're probably getting the most from the system.
- ◆ If you answered YES to all or some of questions 1, 3, 5, 7, 9, 11, 17, or 19: You may be a passive health care consumer. The good news is that you can change. Begin by doing the things listed in questions 2, 4, 6, 8, 10, 12-16, and 18. The more active you are in your health care, the greater the chance that you will receive the health care services you need.

Adapted from: Kailes, J. I. (2005). *Be a Savvy Health Care Consumer, Your Life May Depend on It!* KAILES Publications. Available at <http://www.jik.com/resource/html> or from [jik@pacbell.net](mailto:jik@pacbell.net)

## Health Care Visit Strategy Quiz

Take this quiz to see if you make the best use of very limited time during your visits with a health provider.

Yes	No	Before your visit, do you:
		Plan ahead and ask for any disability specific assistance you will need to have productive visits with health providers (interpreters, height adjustable exam table, consent forms and instructions in Braille, large print, disks, audio cassette)?
		Ask how much time is available for your visit?
		Ask for an appointment when provider is less likely to be rushed (such as the first appointment of the day or right after lunch)?
		Mail, fax, or e-mail a copy of your questions and concerns list or give a copy to receptionist, to give to your provider, when you arrive?
		When possible, mail, fax, or e-mail current and short health history to a new provider before visit and then ask if the provider has read it?
		<b>During your visit, do you:</b>
		Let your provider know that you have questions?
		State your major concerns and what you want to discuss?
		Create a "questions and concerns list," placing the most important items first?
		Leave space between each question and concern to take notes?
		Communicate information briefly and clearly?
		Work with a support person, if helpful?
		Present a current and short health history that explains your condition(s) (when seeing new providers)?
		Provide important information about your condition/disability, if you are not asked?
		Give providers relevant information about how your disability affects your health care?
		Share useful written information about your disability or condition with provider?
		Take notes and/or tape record your discussion with providers?
		Ask providers to add to their explanations by using pictures and models, when needed?
		Make sure to get the appropriate routine screenings?
		Take time to think about what you're being told before making an important decision?
		Ask for sources of additional information: books, articles, web sites, videos or support groups?
		At the end of a visit, check your understanding by briefly repeating what you heard the provider say?



## Health Care Visit Strategy Quiz (continued)

Yes	No	During your visit, do you: (continued)
		Establish friendly relationship with the provider's staff so they will remember you, especially when you call to ask for something?
		<b>After your visit, do you:</b>
		Follow-up to get your test results?
		Update your medical records?
		Get a opinion from another provider if you think you need one?

### Your Answers

Unless you answered YES to all of these questions you still have room for improvement. Begin by working on developing ways to deal with the items for which you checked "NO."

If you answered NO to 10 or more of the questions, begin to work on adding these approaches to what you will do during future visits with health care providers.

Adapted from: Kailes, J. I. (2005). *Be a Savvy Health Care Consumer, Your Life May Depend on It!* KAILES Publications. Available at <http://www.jik.com/resource/html> or from [jik@pacbell.net](mailto:jik@pacbell.net)

## Why Is It Important to Plan Ahead?

If you have a disability, you should get the same quality of health care given to people without disabilities. To help ensure that you get good care, plan ahead. Ask for any disability-specific assistance you need to complete successful visits. Even if you have seen health care providers before, it is helpful to remind them about your specific needs.

Review the list of items on the next page, check off those that apply to you, and remind providers about your needs before and when you meet with them. Before your appointment, call to ask about the items marked with an asterisk (\*).

For example:

- ◆ If you need an interpreter for a non-emergency appointment, providers need to have notice (sometimes several weeks) in order to have one available.
- ◆ If you need assistance transferring to an exam table, your provider may need time to plan to arrange to have people available who can help you.

Use this list to think about items that would be helpful or critical for you to request from health care providers. You can also help educate your health care providers by sharing Tips for Health Care Providers (Part 5) with them.



## Checklist for Planning Ahead if You Need Disability-Specific Assistance?

✓	Check all items that apply to you:
	A support person who assists me will accompany me. However, I make my own decisions and want health providers to discuss my choices with me directly. Providers should speak directly to me rather than to or through my support person.
	I need providers to use “everyday” plain language and to pause often, to be sure that I am following what they are saying.
	I need providers to give me information that is clear and understandable.
	I need providers to use pictures or models. Sometimes I need them to demonstrate how to do something.
	I need to ask questions that are important to me, and I need providers to be patient when I am trying to understand new information.
	A slow response or lack of response does not necessarily mean I am not aware of what is being said. Providers should allow extra time for me to respond.
	I read lips and I need people to face me when speaking to me. Therefore:
	<ul style="list-style-type: none"><li>• People should keep their hands away from their mouth when speaking.</li></ul>
	<ul style="list-style-type: none"><li>• People should use their normal tone of voice when talking with me.</li></ul>
	<ul style="list-style-type: none"><li>• People should raise their voice so I can hear what they are saying to me.</li></ul>
	I am deaf and need to use an interpreter to sign conversations:
	<ul style="list-style-type: none"><li>• American Sign Language (ASL)</li></ul>
	<ul style="list-style-type: none"><li>• Signed English</li></ul>
	<ul style="list-style-type: none"><li>• Oral</li></ul>
	<ul style="list-style-type: none"><li>• I will use a family member or friend.</li></ul>
	<ul style="list-style-type: none"><li>• The speaker should speak directly to me and not the interpreter.</li></ul>
	<ul style="list-style-type: none"><li>• Other:</li></ul>
	I need to have consent forms and instructions read to me.
	I need consent forms and instructions provided in this format:
	<ul style="list-style-type: none"><li>• Braille</li></ul>
	<ul style="list-style-type: none"><li>• Large print</li></ul>
	<ul style="list-style-type: none"><li>• Computer disk</li></ul>
	<ul style="list-style-type: none"><li>• Audio (tape, CD-ROM, MP3)</li></ul>
	I need assistance in filling out forms.



## Checklist for Planning Ahead if You Need Disability-Specific Assistance (continued)

✓	Check all items that apply to you:
	I would like to have all forms I must complete sent to me before my appointment. I will read them, complete them, and bring them with me to the appointment.
	My speech is slow and/or difficult to understand.
	<ul style="list-style-type: none"><li>• Please allow extra time so I can ask questions.</li></ul>
	<ul style="list-style-type: none"><li>• Please avoid acting as if you understand me, unless you do.</li></ul>
	<ul style="list-style-type: none"><li>• If what I say is not understood, ask me to repeat it, even three or four times, if needed.</li></ul>
	If what I say is still not understood, ask me to:
	<ul style="list-style-type: none"><li>• Use paper and pen.</li></ul>
	<ul style="list-style-type: none"><li>• Spell the words.</li></ul>
	<ul style="list-style-type: none"><li>• Other:</li></ul>
	I use a communication device or a communication board.
	<ul style="list-style-type: none"><li>• Please try not to interrupt or finish my sentences.</li></ul>
	<ul style="list-style-type: none"><li>• It is OK to interrupt or finish my sentences.</li></ul>
	<ul style="list-style-type: none"><li>• Please allow for extra time so I can ask questions.</li></ul>
	<ul style="list-style-type: none"><li>• Other:</li></ul>
	I need to know if the building, office, exam rooms, scales and equipment are wheelchair-accessible.*
	<ul style="list-style-type: none"><li>• I need a height-adjustable (high/low) exam table• and/or</li></ul>
	<ul style="list-style-type: none"><li>• I need help getting onto an exam table.*</li></ul>
	I need to use a wheelchair-accessible restroom.*
	I need to take an accessible bus that has an accessible route from the bus stop to the office.*
	I need an accessible parking space and an accessible route (including an elevator if not on entry level) into the health provider’s office.*
	If I am referred to another provider (such as a specialist) for consultations, procedures, or tests, I need to be sure that the facilities and equipment are accessible and/or staff are willing and able to provide assistance with:
	<ul style="list-style-type: none"><li>• Transfers</li></ul>
	<ul style="list-style-type: none"><li>• Positioning</li></ul>
	<ul style="list-style-type: none"><li>• Other:</li></ul>
	I use a service dog, so please alert anyone who is allergic to or frightened of dogs.*



## Checklist for Planning Ahead if You Need Disability-Specific Assistance (continued)

<b>✓</b>	<b>Check all items that apply to you:</b>
	I have <input type="checkbox"/> life-threatening or <input type="checkbox"/> health-threatening reaction to:
	• Latex
	• Pesticides
	• Roofing sealant
	• Paint
	• Scented personal care products
	• Other:
	I will need to reschedule my appointment if I will be exposed to the above products.
	My provider should consider developing a scent-free workplace policy.

### Sources:

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## How Can You Improve Your Communication with Your Health Care Providers?

This section offers advice and tools to help you improve your communication with health care providers. Expressing your needs, letting providers know what you want, and asking questions will help you get the right health care services. This is true for anyone, but it may be truer for people with disabilities. This is because

providers may make assumptions about you and your health.

When talking with health care providers:

- ◆ **Be active and assertive.** Ask for what you want or need, or bring up questions or issues of concern. Active, assertive communication will help you stay in control.
- ◆ **Avoid being passive.** Don't wait for information or for results to happen.

Passive communication gives your power away.

- ◆ **Be specific.** Give enough detail for the provider to act on your request. Non-specific communication is fuzzy and unclear.
- ◆ **Be results-oriented, not problem-oriented.** Effective communication is solution-specific and results-oriented. Stating problems only gives away your personal power and leaves it to the other person to figure out the solution. It is passive and removes you from responsibility for the outcome. If your

communication style is results-oriented, health care providers will know what you feel the solution is. They can then use that information to make decisions with you.

- ◆ **Don't stop or give up.** Be respectful but firm, in asking for what you need.

### Should You Speak Up?

Here are some examples of helpful and not helpful communication:

Types of Communication	
Helpful	NOT Helpful
<p><b>Active Communication</b>            "I believe I need to have my blood pressure, cholesterol, and weight checked. I also need a flu shot."</p>	<p><b>Passive Communication</b>            "Well, I thought I might need some tests and some shots, but I guess if you don't see anything that needs to be looked at...I mean, you're the doctor."</p>
<p><b>Specific Communication</b>            "I need a referral to a mammogram center that can work with people like me who are unable to stand."</p>	<p><b>Non-Specific (Fuzzy) Communication</b>            "I need to get a breast check up."</p>
<p><b>Results-Oriented Communication</b>            "I would like to have my physical while on the exam table. I need assistance getting on the exam table."</p>	<p><b>Problem-Oriented Communication</b>            "I don't want to have my physical while seated in my scooter."</p>
<p><b>Persistent Communication</b>            "I know you have other patients waiting, but I really feel that this is important. I think I'm overweight and I smoke too much. Could you take a few minutes to discuss these issues with me?"</p>	<p><b>Non-Persistent Communication</b>            "That's OK. I think I'm overweight and I smoke too much, but I understand that you're running short on time."</p>

## The DES Script: A Tool for Improving Communication

People who communicate their health care needs clearly can achieve better results. The DES Script described below can help you sharpen your communication skills. This tool reminds you to think and speak in ways that will help you:

- ◆ Feel more confident as you express your needs.
- ◆ Help lessen other people's feelings that you are attacking them.
- ◆ Make sure you state that what you want to get out of a situation.

### The DES Script

The DES Script breaks down statements into three pieces:

- D** Describe the situation as you see it.
- E** Express how you feel about it, using "I" statements, such as "I feel . . ." or "I believe . . ."
- S** Specify what you want to see done, changed, accomplished.

The key to using this tool effectively is practice. Some examples are given below.

#### Situation

The doctor is rushing through your appointment because she is running late and there are many other patients waiting.

#### Response

- |          |   |
|----------|---|
| <b>D</b> | It seems like you're in a hurry and I have several concerns we haven't discussed.           |
| <b>E</b> | I feel like my needs are not being met, and I'm not OK with that.                           |
| <b>S</b> | What can we do to make sure we get the chance to discuss my questions before I leave today? |

#### Situation

The doctor begins to give you your annual physical while you are still seated in your wheelchair. You want the exam to be done on the exam table.

#### Response

- |          |  |
|----------|--|
| <b>D</b> | I have concerns about not getting a complete physical while seated in my wheelchair. |
| <b>E</b> | I feel like I'm not getting the best treatment possible.                             |
| <b>S</b> | I would like to have my physical while on the exam table.                            |

**Situation**

You feel that you're gaining weight and you've been unsuccessful in stopping smoking, but the doctor never discusses these concerns.

**Response**

**D** We never discuss my diet, eating, and smoking habits.

**E** I'm concerned about my weight and my smoking.

**S** I need to discuss these concerns with you.

**Situation**

You know you're at risk of osteoporosis because of your size and family history, and because you've had a spinal cord injury. You're only 30 years old, but you're concerned about the future.

**Response**

**D** Because of my walking limitations, I don't do a lot of walking or standing.

**E** I'm only 30 but I feel worried about my bone density.

**S** I want you to help me get a bone-density test to see if I have a problem.

**Situation**

You're having your annual checkup. You use a walker, but you don't have the balance needed to step up onto the scale and stand on it. The nurse says, "Since we can't weigh you, tell me what you think your weight is."

**Response**

**D** I want to be weighed like everyone else.

**E** Don't you base my medications dosages on my height and weight?

**S** Can you get an accessible scale that I can use?

**Situation**

On your last doctor visit, you found that you weren't able to get onto the exam table. The staff was not prepared to transfer you safely and there were no options. When you schedule your next appointment, you call ahead to plan.

**Response**

**D** On my last visit, I found that your high exam table doesn't work for me.

**E** I would be able to safely get on to a height-adjustable table that lowers to 18-20 inches.

**S** Can you get one? Here's a list of some of the available tables.

**Situation**

Because of your disability, you have trouble maintaining the position needed for a mammogram. As a result the images aren't always clear. You feel you also need screening using ultrasound. The imaging center's staff says that that's not possible because of their policies.

**Response**

<b>D</b>	I have a history of unclear mammography films because it's hard for me to stay in the position needed.
<b>E</b>	I would like an ultrasound in addition to the mammography.
<b>S</b>	I need your help to make this happen.

Now you practice thinking and planning clearly. Think of three situations that might come up for you at a provider visit. What response could you give for each of these situations?

- ◆ How would you “Describe” this?
- ◆ What words might best “Express” how you would feel?
- ◆ How can you “Specify” what you want done?

<b>D</b>	
<b>E</b>	
<b>S</b>	

<b>D</b>	
<b>E</b>	
<b>S</b>	

<b>D</b>	
<b>E</b>	
<b>S</b>	



## How Can You Understand and Remember Information from Visits with Health Care Providers?

Sometimes you may not be able to remember or explain what your provider told you at your appointment. Your friends and family may ask what your doctor said, but you are not sure or you cannot remember. People may ask you questions that you wish you had asked during your



visit. You are not alone. Below are ways to help you understand and remember what happens at your appointments.

### Take a Support Person with You

To make the most of your appointment, think about taking a support person with you. A support person can be a friend or family member who you trust. A support person is someone who listens, takes notes, and asks questions. A support person can also help you remember what the doctor says. Remember, it's your right to always bring one support person into your appointment with you.

When choosing a support person, make sure the person is:

- ◆ Someone you trust.
- ◆ Someone who will not take control of the visit.
- ◆ Someone you can rely on for support.
- ◆ Someone who can listen carefully and take good notes.

### Making the Most of Your Support Person: A Checklist

- ✓ Before your appointment, tell your support person what you need. For example, you may want some private time with your provider. If so, tell your support person about this need.
- ✓ Introduce your doctor to your support person. Make sure your doctor talks both to you and your support person.
- ✓ Make sure that you and your support person take notes. If you cannot take notes, sit close to your support person. This will allow you to refer to your support person's notes if you need to.
- ✓ After your appointment, compare notes with your support person. Make sure you understand what the provider said.

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After choosing a support person, work together to get the most from your appointment. Use the checklist below to make sure your appointment goes smoothly.

### **Take Notes**

It is said that “The faintest ink is more accurate than the strongest memory.” On average, 50 percent of what people are told is forgotten in minutes. During a health care appointment, take notes about important information or ask your support person to do so.

During your appointment, take notes on what your provider says. You can also ask your support person to take notes for you.

At the end of your appointment, review the information with your provider. Tell your provider what you thought her main points were. If your provider corrects you, change your notes.

### **Tape Record Your Appointments**

Sometimes you may not want or be able to take notes. You may not be able to find a support person. You can tape record your appointment. This will help you focus on what your provider says without missing any important information.

Before you record an appointment, tell your provider why you want to record what she says. For example, you might say, “Do you mind if I tape our appointment?”

I do not want to miss anything you say by taking notes. I want to remember everything I hear, and recording helps me.”

### **Ask for Pictures**

If you do not understand something your provider says, ask her to show you on a model or draw a picture. Ask for a copy of the picture.

## **How Can You Be Sure to Get Your Test Results?**

Never assume things are OK when you don’t hear from your doctor about your test results. Studies show most providers do not always follow up on test results. Be assertive and follow up if you don’t get your test results. The results are more important to you than to anyone else. Tell your provider you want to be called about the results, whether they are positive or negative, as soon as possible. Also, request a copy of them for your records. Don’t consider the test complete until you get the results.

Also be sure that your test results and routine screening results are shared with other health care providers who are active in your care. Having these results:

- ◆ Helps them stay current and informed regarding your health
- ◆ Prevents time delays when they need



the information to make treatment decisions

- ◆ Prevents tests from being repeated unnecessarily
- ◆ Reminds them that there are other people involved in your care that they may need to consult

Use the form below to help ensure that you and your providers get copies of your test results. Give a copy of this form to the provider who orders or does the test.

## Important Ideas to Remember

- The most successful relationships with health care providers are when they are viewed as partnerships with the patient.
- You will get better results in your health care if you are active than if you are passive.
- Good communication can lead to better health care.
- If you plan ahead to get help at your appointment that is specific to your disability, you will most likely get better care and services.
- Take a support person with you to your appointment to get more out of it.

## Test Result Communication Form

Please send my test results to:

### Patient\*:

Address

City

State

Zip

Phone:

Fax:

### Primary Care Provider:

Address

City

State

Zip

Phone:

Fax:

### Provider:

Address

City

State

Zip

Phone:

Fax:

### Provider:

Address

City

State

Zip

Phone:

Fax:

### Provider:

Address

City

State

Zip

Phone:

Fax:

### Provider:

Address

City

State

Zip

Phone:

Fax:

### Comments:

\*Always include yourself on the lists of individuals who are to receive your test results.

Adapted from: Kailes, J. I. (2005). *Be a Savvy Health Care Consumer, Your Life May Depend on It!* KAILES Publications. Available at <http://www.jik.com/resource/html> or from [jik@pacbell.net](mailto:jik@pacbell.net)

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## Notes

## Part 5

# Resources

When it comes to screening tests and vaccines, remember that not everyone needs the same ones. Check with your health care provider to find out which screenings and vaccines you should get.

## What Else Should You Know About Routine Screenings and Vaccines?

The two tables below provide more information about some screening tests and vaccines. Remember that one size doesn't fit all. Check with your health care provider to find out which screenings you should have. See Organizations and Web

Sites later in Part 5 for more information.

There are words in the charts below that can be unclear to many people. There are a lot of medical and health words that may be new to you. You should bring these charts with you to your doctors and ask them which of these screening tests are important for you. He or she can explain them to you.

### More about Routine Screening Tests

The Problem	Screening Test	How the Screening Test Helps
<b>Cancers</b>		
Breast cancer	Mammogram	<ul style="list-style-type: none"><li>• A mammogram is an X-ray picture of your breast. It can detect cancer or a lump that is too small for you or a doctor to find.</li><li>• Finding a problem, such as a small lump, early can lead to treating breast cancer in its earliest, curable stage.</li><li>• Your first screening is called a baseline mammogram. It will be compared to future mammograms to look for changes that may suggest cancer.</li></ul>

## More about Routine Screening Tests (continued)

The Problem	Screening Test	How the Screening Test Helps
<b>Cancers (continued)</b>		
Breast Cancer (continued)	Clinical breast exam	<ul style="list-style-type: none"> <li>The clinical breast exam helps detect lumps or breast changes that might be early signs of breast cancer.</li> <li>Your doctor or another trained health care professional can do a manual breast exam during a checkup.</li> </ul>
	Breast self-examination (BSE)	<ul style="list-style-type: none"> <li>Monthly self-exams help you learn what is normal in your breasts. They can also help find lumps or other problems early.</li> <li>Beginning at age 20, you should check your breasts at the same time each month. A health care professional can show you how to do BSE.</li> </ul>
Cervical cancer	Pap test	<ul style="list-style-type: none"> <li>Cervical cancer is one of the most common cancers that affect women's reproductive organs. Cervical cancer is often caused by human papillomavirus (HPV), the virus that causes genital warts.</li> <li>The Pap test collects cell samples from your cervix and vagina. The samples are checked for abnormal cells.</li> <li>The test can find cancer or possible precancerous changes that can be treated in the early stages.</li> <li>The Pap test is done when you have a pelvic exam during a gynecological checkup.</li> </ul>
Colon and rectal (colorectal) cancer	Fecal occult blood test (FOBT)	<ul style="list-style-type: none"> <li>The FOBT chemically checks your stool for hidden (occult) blood.</li> <li>Occult blood in the stool may suggest cancer or polyps (small, protruding clumps of cells on the inside wall of the colon and rectum).</li> </ul>
	Flexible sigmoidoscopy	<ul style="list-style-type: none"> <li>To do this test, a doctor uses a flexible, slender, lighted tube to look at your rectum and sigmoid (the last two feet of your colon). Nearly half of all colon cancers occur in this area.</li> </ul>
	Colonoscopy	<ul style="list-style-type: none"> <li>This test is used to visually examine your entire colon and rectum for abnormalities.</li> <li>During the exam, a long, flexible tube (colonoscope) is inserted into the rectum. A tiny video camera at its tip lets the doctor view the inside of the colon.</li> <li>If a polyp or abnormal tissue is found, the doctor may remove it during the test or take a biopsy (sample) of it. The doctor might also suggest that the tissue be removed later.</li> </ul>

## More about Routine Screening Tests (continued)

The Problem	Screening Test	How the Screening Test Helps
<b>Cancers (continued)</b>		
Colon and rectal (colorectal) cancer (continued)	Barium enema (colon X-ray)	<ul style="list-style-type: none"> <li>A barium enema test is an X-ray test. Liquid barium is inserted into the lower bowel through the rectum. It is usually followed by injection of air to inflate the bowel during the test.</li> </ul>
Prostate cancer	Digital rectal exam (DRE)	<ul style="list-style-type: none"> <li>Prostate cancer affects the prostate gland, which produces fluid that nourishes and transports sperm.</li> <li>During a DRE, your doctor inserts a gloved, lubricated finger into your rectum to examine your prostate, which is adjacent to the rectum.</li> <li>If the doctor finds that the gland has an abnormal texture, shape, or size, you may need more tests.</li> </ul>
	Prostate-specific antigen (PSA) test	<ul style="list-style-type: none"> <li>A blood sample is drawn from a vein and analyzed for PSA. PSA is naturally produced by the prostate gland to help liquefy semen.</li> <li>Higher than normal PSA levels may suggest that you have prostate infection, inflammation, enlargement, or cancer.</li> </ul>
	Urine test	<ul style="list-style-type: none"> <li>A urine sample is analyzed for abnormalities that may indicate a problem.</li> <li>The urine test does not detect prostate cancer, but it can help detect or rule out other problems that may cause similar signs and symptoms.</li> </ul>
<b>Other Conditions</b>		
Diabetes	Fasting blood glucose test	<ul style="list-style-type: none"> <li>Diabetes is group of diseases that affect the way the body uses blood sugar (glucose). Glucose is vital to health because it is the body's main source of fuel.</li> <li>Normally, glucose is able to enter your cells because of the action of a hormone called insulin. When a person has diabetes, this process doesn't work well and glucose accumulates in the bloodstream. Accumulation of glucose in the blood can damage almost every major organ in your body.</li> <li>The fasting blood glucose test looks at the level of glucose in your blood.</li> </ul>
High Cholesterol	Cholesterol test	<ul style="list-style-type: none"> <li>When cholesterol levels in your bloodstream become too high, fatty deposits (plaque) can form in your arteries. This can reduce blood flow and lead to heart attack or stroke.</li> <li>High cholesterol has no symptoms. The only way to find out if you have high cholesterol is a blood test.</li> </ul>



## More about Routine Screening Tests (continued)

The Problem	Screening Test	How the Screening Test Helps
<b>Other Conditions (continued)</b>		
High Blood Pressure (hypertension)	Blood pressure check	<ul style="list-style-type: none"> <li>• If uncontrolled, high blood pressure can lead to stroke, heart attack, heart failure, or kidney failure. The only way to tell if you have high blood pressure is to have your blood pressure checked.</li> <li>• Blood pressure measurement consists of two numbers: systolic (the pressure of blood against your artery walls when the heart has just finished pumping) and diastolic (the pressure of blood against your artery walls between heartbeats, when the heart is relaxed).</li> <li>• A blood pressure measurement is written as systolic/diastolic. Normal blood pressure is 119 or below/79 or below. High blood pressure is 140 or above/90 or above.</li> </ul>
Osteoporosis	Bone-density test (DEXA scan)	<ul style="list-style-type: none"> <li>• Osteoporosis involves thinning and weakening of the bones, especially bones in the hip, spine, and wrist, to the point where they break easily.</li> <li>• Bone loss occurs when the body naturally removes more bone than it replaces. Bone loss may begin slowly in some people when they are in their late thirties. At the time of menopause, women may lose bone quickly for several years.</li> <li>• Losing height or having a bone break easily is often the first sign of osteoporosis.</li> <li>• A test called a DEXA scan accurately measures bone density.</li> </ul>
Overweight/ Obesity	Weight measurement	<ul style="list-style-type: none"> <li>• Being overweight or obese increases your risk of high blood pressure, diabetes, heart disease, gallbladder disease, stroke, osteoarthritis (wearing away of the joints), sleep apnea (breathing stops for short periods of time during sleep), and cancer.</li> <li>• Keeping an eye on your weight is important. Your doctor can help you decide whether you need to lose weight and, if so, how much. The doctor can review your medical history with you to determine how dangerous excess fat is to your health.</li> <li>• Your doctor can also suggest ways to lose weight if you need to.</li> </ul>

## More about Vaccines

The Problem	How the Vaccine Helps
Influenza (flu)	<ul style="list-style-type: none"> <li>• Flu is an infection that spreads easily. It causes fever, chills, dry cough, sore throat, runny or stuffy nose, headache, muscle aches, and often extreme fatigue.</li> <li>• Flu usually is a mild disease. However, it can be life-threatening in older adults and people with chronic respiratory conditions and other risk factors.</li> <li>• Flu viruses change all the time. For this reason, it is important to get a flu shot every year if you are in one of the risk categories (see Recommended Vaccines table above). To give your body time to build the proper defense, get a flu shot between September and mid-November, before the flu season usually starts.</li> </ul>
Pneumococcal disease (pneumonia)	<ul style="list-style-type: none"> <li>• Pneumococcal disease is a serious infection. Many people know about pneumococcal pneumonia, which affects the lungs.</li> <li>• The bacteria that cause pneumococcal pneumonia can also attack other parts of the body. This can lead to meningitis (inflammation around the brain or spinal cord), bacteremia (bacteria in the blood), middle ear infections, and sinus infections.</li> <li>• Pneumococcal disease is treated with antibiotics. However, in recent years the bacteria that cause pneumococcal disease have become more and more resistant to penicillin, a common antibiotic used to treat pneumonia. This is one reason why prevention and getting a vaccine is so important.</li> </ul>
Tetanus (lockjaw)	<ul style="list-style-type: none"> <li>• Tetanus is caused by the toxin (poison) of a bacterium. It can enter the body through a tiny pinprick or scratch. It can also enter through a deep puncture wound or cut. Tetanus bacteria are commonly found in soil, dust, and manure.</li> <li>• Tetanus is not spread from person to person. Common first signs of tetanus are headache and muscle stiffness in the jaw, followed by stiffness of the neck, difficulty swallowing, muscle spasms, sweating, and fever.</li> <li>• A tetanus shot can help prevent the disease.</li> </ul>
Diphtheria	<ul style="list-style-type: none"> <li>• Diphtheria usually affects the tonsils, throat, nose, or skin. It is caused by a bacterium and spreads from an infected person to the nose or throat of others.</li> <li>• This disease can lead to breathing problems, heart failure, paralysis, and sometimes death. It may be mistaken for a severe sore throat. Other symptoms include a low-grade fever and enlarged lymph nodes in the neck. One form of diphtheria causes sores on the skin that may be painful, red, and swollen.</li> <li>• Diphtheria is very rare in the United States. The vaccine is a precaution against the disease.</li> </ul>

## More about Vaccines (continued)

The Problem	How the Vaccine Helps
Chickenpox (varicella)	<ul style="list-style-type: none"> <li>• Chickenpox is a very contagious disease caused by a virus. It spreads easily through the air by infected people when they sneeze or cough. It also spreads through contact with an infected person’s chickenpox sores. People who have never had chickenpox can get infected just by being in the room with someone who has the disease.</li> <li>• Early chickenpox symptoms include aching, tiredness, fever, and sore throat. An itchy, blister-like rash appears later.</li> <li>• Chickenpox is a mild disease for children. Adults usually get much sicker.</li> <li>• The chickenpox vaccine can help prevent the disease.</li> </ul>
Measles, mumps, and rubella (MMR)	<ul style="list-style-type: none"> <li>• Measles, mumps, and rubella were once very common diseases in the United States. Today, they are rare because of the use of vaccines to prevent them.</li> <li>• As with many other diseases, measles, mumps, and rubella generally are more severe in adults than in children. Most adults are immune to all three infections because they had them (or were vaccinated) as children.</li> </ul>
Hepatitis A	<ul style="list-style-type: none"> <li>• Hepatitis A is a liver disease caused by a virus. In the United States, it can occur in situations ranging from isolated cases of disease to widespread epidemics.</li> <li>• Good personal hygiene and proper sanitation can help prevent hepatitis A. Vaccines are also available for long-term prevention of hepatitis.</li> </ul>
Hepatitis B	<ul style="list-style-type: none"> <li>• Hepatitis B is a serious disease caused by a virus that attacks the liver. It is one of the most easily spread forms of viral hepatitis. It occurs when blood or body fluids from an infected person enter the body of a person who is not immune.</li> <li>• This disease is spread through having sex with an infected person without using a condom; by sharing drugs, needles, or “works” when using injection drugs; through needlesticks or sharps exposures on the job; or from an infected mother to her baby during birth.</li> <li>• The hepatitis B vaccine is the most effective way to prevent infection. This vaccination involves getting 3 shots given at different times.</li> </ul>
Polio	<ul style="list-style-type: none"> <li>• Polio is caused by a virus that enters the body through the mouth. Sometimes it does not cause serious illness. Sometimes it causes paralysis or death.</li> <li>• No polio has been reported in the United States for more than 20 years, but the disease is still common in some parts of the world.</li> <li>• Most adults do not need polio vaccine because they were vaccinated as children. However, some people should get the vaccine if they have not had it before (see Recommended Vaccines table above).</li> </ul>

## Quiz: How Much Do You Know About Routine Screenings?

1. \_\_\_ You are an active health care consumer when you (choose one):
- A. Take responsibility for your health
  - B. Are a partner and co-manager in your health care
  - C. Share in the decision making process
  - D. All of the above

### True or false:

- 2. \_\_\_ For many people, the first sign of heart disease is death.
- 3. \_\_\_ People with physical disabilities are less likely than the general population to be affected by preventable health conditions.
- 4. \_\_\_ People with disabilities have greater access to and higher rates of routine screening when compared to the general population.
- 5. \_\_\_ Health providers often do not address sexual, diet, and exercise issues with people with disabilities.
- 6. \_\_\_ Knowing your health risks can help you and your doctor decide what preventive screenings you need and when to get them.
- 7. \_\_\_ It is safe to assume that your health care provider will take care of all your routine screenings.
- 8. \_\_\_ People with disabilities develop conditions like cancer, high blood pressure, and high cholesterol just like people without disabilities.
- 9. \_\_\_ Diabetes is a group of diseases that affect the way your body uses blood sugar (glucose). This sugar is vital to your health because it is your body's main source of fuel.
- 10. \_\_\_ The accumulation of glucose in your blood can damage almost every major organ in your body.
- 11. \_\_\_ High blood pressure can lead to stroke, heart attack, heart failure, or kidney failure.
- 12. \_\_\_ High cholesterol has no symptoms. The only way to find out if you have high blood cholesterol is by having a blood test.

13. \_\_\_ When a person has osteoporosis, the body removes more bone than it makes. This means bones get weaker and are more likely to break.
14. \_\_\_ The most common way to measure bone density is by a DEXA scan. This scan measures the thickness (density) of your bones.
15. \_\_\_ Routine Pap tests can help detect cervical cancer.

**Answers to Quiz**

- |                         |          |          |
|-------------------------|----------|----------|
| 1. D (All of the above) | 6. True  | 11. True |
| 2. True                 | 7. False | 12. True |
| 3. False                | 8. True  | 13. True |
| 4. False                | 9. True  | 14. True |
| 5. True                 | 10. True | 15. True |

## Organizations and Web Sites

There is a lot of health information available on the Internet. It can be hard to decide where to begin. What information should you trust, and how do you make sense of the recommendations provided? Below are a few links to get you started.

Use the Internet to keep up with the most current information. Be sure you discuss any information or recommendations you find with your doctor. Everything you read will not apply to your situation.

### General Health Information

#### Healthfinder.gov

[www.healthfinder.gov](http://www.healthfinder.gov)

The U.S. government's health information. Includes links to online journals, medical dictionaries, and prevention and self-care information.

#### Health Status Internet Assessments

[www.healthstatus.com/calculators.html](http://www.healthstatus.com/calculators.html)

Offers tools to automatically estimate or calculate:

- ◆ Blood alcohol level
- ◆ Body mass index
- ◆ Body fat
- ◆ Lean body mass



- ◆ Calories burned
- ◆ Daily energy expenditure
- ◆ Ideal weight
- ◆ How long it takes to lose one pound
- ◆ Smoking costs
- ◆ Target heart rate

#### Health, Wellness and Aging with Disability Resources

[www.jik.com/hwawd.html](http://www.jik.com/hwawd.html)

#### Kaiser Permanente Health Information

<http://prospectivemembers.kaiserpermanente.org>

Offers information about a variety of health topics (click on "Your Health").

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## Mayo Clinic

[www.mayoclinic.com](http://www.mayoclinic.com)

A reliable resource for all of the conditions covered in this Resource Guide. Offers easy-to-understand information on health and medical topics, all reviewed for accuracy by Mayo Clinic experts. Content includes information on specific conditions, management of particular chronic conditions, suggestions for healthy lifestyles, consumer drug information, first aid, specialists' answers to frequently asked questions about diseases and health decision-making guides.

## MedlinePlus

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

Operated by the National Library of Medicine, provides access to more than 700 health topics, drug information, a medical encyclopedia, a medical dictionary, health news, links to self-help groups, clinical trials, pre-formulated PubMed searches, lists of hospitals and physicians, and information in Spanish and other languages.

## Project SHIELD

[www.project-shield.org](http://www.project-shield.org)

Provides information about seeking preventive health care and information about Project SHIELD's research and training activities.

## U.S. Preventive Services Task Force

[www.ahrq.gov/clinic/uspstfix.htm](http://www.ahrq.gov/clinic/uspstfix.htm)

An independent panel of experts that reviews evidence and recommendations regarding routine screenings.

## Physical Activity Information

### Disabled Sports USA

[www.dsusa.org](http://www.dsusa.org)

451 Hungerford Dr., Suite 100  
Rockville, MD 20850  
301-217-0960

Offers nationwide sports rehabilitation programs to anyone with a permanent physical disability.

### National Institute on Aging

[www.nia.nih.gov](http://www.nia.nih.gov)

Offers *Exercise: A Guide from the National Institute on Aging*, a guide for anyone who wants to take the first steps toward an active lifestyle (available at <http://www.nia.nih.gov/HealthInformation/Publications/ExerciseGuide/>). People with a variety of disabilities and activity limitations can easily adapt, tailor, and use this information.

### National Center on Physical Activity and Disability

[www.ncpad.org](http://www.ncpad.org)

1640 W. Roosevelt Road

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Chicago, IL 60608-6904  
800-900-8086 (voice and TTY)

Offers fitness resources and encourages people with disabilities to engage in regular physical activity as a means of promoting healthy lifestyles and preventing development of secondary conditions.

### **Accessibility Information**

#### **National Center on Accessibility**

[www.ncaonline.org/index.shtml](http://www.ncaonline.org/index.shtml)  
2805 East 10th Street, Suite 190  
Bloomington, IN 47408-2698  
812-856-4422  
812-856-4421 (TTY)

Focuses on universal design and practical accessibility solutions creating inclusive recreation opportunities for people of all abilities. Offers information on recreation, parks, and tourism.

#### **Tools to Advocate for Your Accessible Health Care**

[www.cdihp.org/products.html](http://www.cdihp.org/products.html)  
800-832-0524 (voice/TTY)  
[ahcs@westernu.edu](mailto:ahcs@westernu.edu)

Tools designed to educate managed care organizations, health care professionals, community organizations, advocates, and people with disabilities. Series includes discussions, examples, illustrations, and resource information for improving access

to health care services, programs, and products. Subjects include:

- ◆ Tools for Decreasing Health Care Barriers
- ◆ Importance of Accessible Examination Tables
- ◆ Importance of Accessible Weight Scales
- ◆ Tax Incentives for Improving Accessibility
- ◆ Health Care Facilities Access
- ◆ ADA Resources
- ◆ Barrier Removal: Improving Accessibility with Limited Resources
- ◆ Choosing and Negotiating an Accessible Business Location

### **Women's Health**

#### **Breast Health Access Project for Women with Disabilities**

[www.bhawd.org/index.html](http://www.bhawd.org/index.html)  
Alta Bates Summit Medical Center  
Herrick Campus  
Rehabilitation Services  
2001 Dwight Way, 2nd Floor  
Berkeley, CA 94704  
510-204-4866  
510-204-4574 (TTY)



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Provides services to a population of women whose breast health needs have been overlooked.

**Center for Research on Women with Disabilities (CROWD)**

[www.bcm.edu/crowd/](http://www.bcm.edu/crowd/)  
713-791-6161

Focuses on issues of health, aging, civil rights, abuse, and independent living. Works to promote, develop, and disseminate information to expand the life choices of women with disabilities so they may fully participate in community life.

**Disabled Women's Network (DAWN) Ontario**

<http://dawn.thot.net/index.html>

Promotes social justice, human rights, and the advancement of equality rights through education, research, advocacy, coalition-building, resource development, and information technology.

**Federal Resource Center for Women with Disabilities**

[www.4woman.gov/wwd](http://www.4woman.gov/wwd)  
1-800-994-WOMAN

Offers summaries about critical health issues for people with physical, neurological, hearing, speech, and visual impairments. Website includes links to sites sponsored by private sector advocacy

groups, and special information on the unique needs and concerns of minority women with disabilities.

**Health Promotion for Women with Disabilities**

[www.nurseweb.villanova.edu/womenwithdisabilities/](http://www.nurseweb.villanova.edu/womenwithdisabilities/)  
610-519-6828

Offers information about a variety of topics related to health and health promotion important for women with disabilities. Topics include aging with a disability, breast health, healthy nutrition and sleep, pregnancy and parenting with a disability, menopause, osteoporosis, making health care choices, communicating with health care providers, home safety, and stress management.

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# Routine Preventive Screening for People with Physical Disabilities: Tips for Health Care Providers

By June Isaacson Kailes

Associate Director, Center for Disability Issues and the Health Professions  
Western University of Health Sciences  
Pomona, California

## The Importance of Preventive Screening for People with Disabilities

People with disabilities have health promotion and disease prevention needs equal to, and sometimes greater than, those of people without disabilities. However, many people with disabilities do not get routine preventive screenings and other important health promotion and disease prevention services. At the same time, people with physical impairments may face increased risks for conditions such as obesity, diabetes, heart and cardiovascular disease, and some cancers because of inactive lifestyles, lack of exercise, and physiological changes associated with disability. For example:

- ◆ In the United States, people with disabling conditions have three to four times as many health problems as people without disabilities. The most common health conditions among people with disabilities include hypertension, diabetes, high cholesterol, obesity, and osteoporosis.<sup>3</sup>
- ◆ Some medical conditions appear to be strongly linked to the primary disabling condition. For instance:
  - People with spinal cord injury develop diabetes at nearly four times the rate of people without disabilities.
  - One of the leading causes of death among people with spinal cord injury is cardiovascular disease.
  - People with cerebral palsy have many more fractures per year than people their age without disabilities.
  - People with limited mobility often have low bone density (some may need to pursue screening for low bone density at age 35 instead of waiting until age 65).
- ◆ People with limited mobility (for example, those with spinal cord injury, cerebral palsy, and post-polio syndrome) can experience certain medical conditions earlier than non-disabled people of the same age.



- ◆ For reasons still not well understood, individuals with disabling conditions are also at greater risk of new medical problems as they get older<sup>1</sup>.

Lack of health promotion and disease prevention activities specific to people with disabilities may further exacerbate the occurrence of secondary conditions within this population.

All of these facts point to the vital need for people with disabilities to get routine preventive screenings at the appropriate time. They also suggest the importance of customized exercise programs and weight-loss strategies for people with disabilities. In fact, these health promotion services could be more valuable for people with disabilities than for others because of their potentially greater beneficial impact within this population.

Encouraging routine preventive health screening is especially important for people with physical disabilities because they may have:

- ◆ Greater risks for acquiring preventable health conditions (such as high blood pressure, diabetes, and osteoporosis), compared to the general population.
- ◆ Less access to and lower rates of routine screening, compared to the general population.
- ◆ Difficulty getting to health care providers' offices because of issues related to transportation (e.g., not having accessible, reliable, and safe transportation) and because of inadequate building and office equipment accessibility.
- ◆ Health care providers who lack disability-specific experience; mistakenly believe that many specific health problems result from the disability; and often do not address general, sexual, diet, and physical activity issues because they focus only on the disability.

### **Ways to Increase Routine Preventive Screening among People with Disabilities**

Problems such as lack of adequate transportation, inaccessible offices and equipment, and attitudinal barriers may

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prevent people with disabilities from visiting their doctors and other health care providers to get needed services. Improving physical access and accommodations, increasing “disability literacy,” and developing disability competency can make it easier for people with disabilities to receive routine preventive screenings. These goals are briefly discussed below.

### **Improve Your Office’s Physical Access**

In order to receive high-quality routine preventive screenings, people with physical disabilities and activity limitations often must get physical, equipment, procedural, and scheduling accessibility and accommodations. Accessibility problems may include transportation problems, barriers getting into the building or offices (e.g., lack of ramps or accessible doorways), and lack of equipment such as exam tables or imaging machines that can be used by people with disabilities.

The Resources section below lists products to assist health care providers in improving accessibility for people with disabilities.

### **Increase Your Disability Literacy**

Health care providers can take steps to increase their own and office staff’s disability literacy. Disability literacy includes understanding:

- ◆ Different kinds of disabilities and activity limitations
- ◆ The importance of being sensitive to the needs of people with disabilities and of interacting effectively and respectfully with individuals with diverse disabilities
- ◆ Legal obligations in complying with the Americans with Disabilities Act (ADA) and other laws so that people with disabilities receive the same quality of health care as that provided to people without disabilities
- ◆ The need to develop and implement office procedures and policies to accommodate people with disabilities
- ◆ How to assess personal prejudices, stereotypes, and biases, and how to overcome them or prevent them from emerging when working with people with disabilities. It is common for people to unknowingly demonstrate bias through their behavior and language. To eliminate bias:
  - Don’t assume that health, wellness, and disability cannot coexist. Physical decline, illness, and other conditions (often referred to as secondary conditions) need not accompany living with a disability.
  - Don’t focus only on an individual’s disability. When health care

providers focus on the disability, they may overlook routine screenings that help prevent major illnesses.<sup>3</sup>

- Don't skip asking about diet, birth control, smoking, drug use, heavy alcohol use, unprotected sex, sexually transmitted diseases, etc. These issues are as important to people with disabilities as they are to other people.
- Don't assume that the more severe a disability, the less an individual's quality of life.
- Don't assume that anyone with a significant disability is depressed.
- Don't assume that people with disabilities do not know about their disability. Treat people as partners in the health care decision-making process.
- Respect the expertise of people who have lived with their disabilities and

unique health care needs. Many individuals have sophisticated knowledge about their own bodies and selected approaches to their health management.

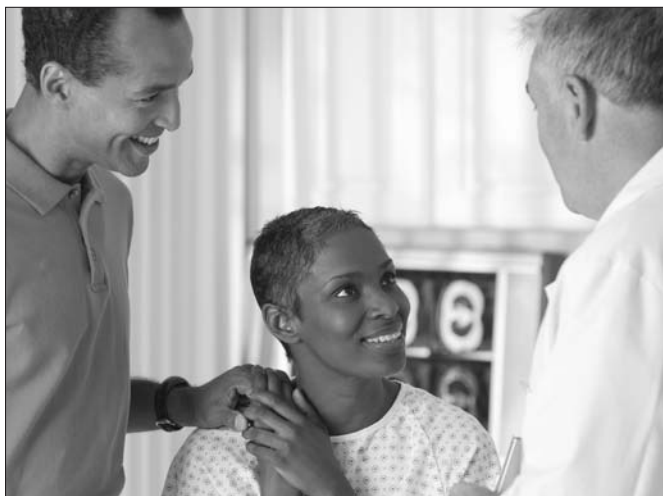
### **Develop Your Disability Competence**

In addition to developing disability literacy, it is important to strengthen your own and your office staff's disability competence. Disability competence includes:

- ◆ Existence of a set of compatible behaviors, beliefs, attitudes, values, practices, skills, and policies. These elements enable a system, organization, or provider to work effectively with a diverse population of people who have disabilities or activity limitations<sup>2</sup>. The elements are continually reinforced through internal evaluation and ongoing education.
- ◆ Knowledge about how to effectively offer accessible programs and services that accommodate and are inclusive of people with disabilities.
- ◆ Understanding and willingness to follow disability-sensitive etiquette, protocols, policies, and procedures.

### **Useful Resources**

**Accessible Health Care Series**  
[www.cdihp.org/products.html](http://www.cdihp.org/products.html)



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This series offers information about improving access to health care services, programs, and products. Topics include:

- ◆ Importance of Accessible Examination Tables
- ◆ Importance of Accessible Weight Scales
- ◆ Tax Incentives for Improving Accessibility
- ◆ Health Care Facilities Access
- ◆ ADA Resources
- ◆ Barrier Removal: Improving Accessibility with Limited Resources
- ◆ Choosing and Negotiating an Accessible Business Location
- ◆ Tax Incentives for Hiring People with Disabilities

### Health, Wellness and Aging with Disability Resources

[www.jik.com/hwawd.html](http://www.jik.com/hwawd.html)

### References

1. Kemp, B. (2001). Aging with a disability: What's been learned? *Orchid: Health and Wellness for women with disabilities, Summer Edition*, NCODH, CB#8185, UNC-CH, Chapel Hill, NC 27599-8185, <http://www.fpg.unc.edu/~ncodh/WomensHealth/Womenshealthpub.htm>
2. Health Resources and Services Administration. (2002). Proceedings of the *Bridging Cultures and Enhancing Care: Approaches to Cultural and Linguistic Competency in Managed Care* conference (May 20, 2002, Chicago, IL). Proceedings available at: <http://www.hrsa.gov/financeMC/bridgingcultures/default.htm#CulturalCompetency>.
3. Mosqueda, L. A. (2004). Maintaining health and function. In B. J. Kemp & L. Mosqueda (Eds.), *Aging with a disability: What the clinician needs to know* (pp. xiv, 307). Baltimore: Johns Hopkins University Press.

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## Notes



## My Risk Factors Checklist

Use this checklist to assess your health risks. Check any item that applies to you, and then share the list with your health care providers. Together, you can create and follow a Routine Screening and Immunization Plan tailored to your needs (see Part 3 of this Guide).

### Breast Cancer

Over age 50 (The chance of getting breast cancer goes up as a woman gets older; 80% of breast cancers occur in women over 50.)

Personal history of breast cancer (A woman who has had breast cancer in one breast has an increased risk of getting this disease in her other breast.)

Family history of breast cancer (especially in your mother, sister, or daughter) (The more relatives you have who got breast cancer before menopause the greater your risk)

History of breast biopsy with atypical (not normal) findings

Family or personal history of gene abnormalities related to breast cancer (Women who are of Eastern and Central European Jewish ancestry are at risk.)

No pregnancies or first pregnancy after age 35

Early onset of menstruation (before age 12)

Late menopause (after age 55)

White (Breast cancer occurs more often in white women than Latina, Asian, or African-American women.)

Overweight /obese

Use of hormone therapy consisting of estrogen plus progestin

Female (Men can develop breast cancer, but it is 100 times more common in women.)

### Cervical Cancer

History of cervical cancer or a pre-cancerous Pap test

History of a sexually transmitted disease

Family history of cervical cancer

Multiple sexual partners

Sexual activity before age 18

A partner who began sexual activity at an early age or who had many previous sexual partners

Infection with human papillomavirus (HPV, the virus that causes genital warts)

Smoking

Exposure to diethylstilbestrol (DES) before birth





## My Risk Factors Checklist (continued)

### Cervical Cancer (continued)

HIV infection

Weakened immune system due to such factors as an organ transplant, chemotherapy, or chronic corticosteroid use

### Colon and Rectal Cancer

History of colorectal cancer or adenomatous polyps (growths that project, usually on a stalk, from the lining of the colon or rectum)

History of inflammatory bowel disease such as Crohn's disease or ulcerative colitis

Family history of colorectal cancer or adenomatous polyps

Evidence of genetic colorectal cancer syndrome

High-fat, low-fiber diet

Smoking

Inactivity/lack of exercise

Extremely overweight (obese)

Diabetes

Heavy alcohol use

Eastern European Jewish descent (particularly Ashkenazi Jews)

### Diabetes

Family history of diabetes (in parents, brothers, or sisters)

Inactivity/lack of exercise

Overweight

Over age 45 (The risk of type 2 diabetes rises with age, especially after age 45.)

African American, American Indian, or Hispanic

### Obesity

Diet of high-calorie foods, such as fast foods, soft drinks, and sweets

Inactivity/lack of exercise

Family history of obesity (in parents)

Overeating to cope with problems or deal with difficult emotions

Use of certain medications (Corticosteroids and tricyclic antidepressants, in particular, can lead to weight gain.)

A medical condition that leads to decreased activity



**My Risk Factors Checklist (continued)**

**Osteoporosis**

	Being a white or Asian woman
	Family history of osteoporosis
	Early menopause (may occur because of early failure of the ovaries, surgical removal of a woman’s ovaries, or chemotherapy for cancer)
	Had surgery to remove ovaries
	Had extended bed rest
	Inactivity/lack of exercise
	Extended use of certain medicines (such as prednisone, cortisone, prednisolone, and dexamethasone)
	Small body frame/very thin
	Smoking
	Heavy alcohol use
	Eating disorder (anorexia nervosa or bulimia)

**Prostate Cancer**

	Male over age 50
	African-American male (Prostate cancer occurs almost 70 percent more often in black men than it does in white men.)
	Family history (in father or brother)
	High-fat diet
	Overweight

**High Cholesterol**

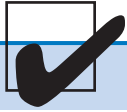
	Inactivity/lack of exercise
	Overweight
	High-fat, high-cholesterol diet
	Smoking
	Type 2 diabetes
	Family history of atherosclerosis (narrowing of the arteries)
	High blood pressure



## My Risk Factors Checklist (continued)

### High Blood Pressure

	Inactivity, lack of exercise
	Family history
	Age (90% of people who, at age 55, do not have hypertension will eventually develop it.)
	African American
	Heavy alcohol use
	Low intake of potassium, magnesium, and calcium
	Overweight/obese
	Smoking
	High sodium (salt) intake
	Sodium/salt sensitivity (People who are sodium sensitive retain sodium. This can lead to fluid retention and high blood pressure.)
	Low potassium intake
	High levels of stress can lead to temporary but striking increase in blood pressure.
	High blood cholesterol
	Diabetes
	Sleep apnea (breathing stops for short periods of time during sleep.)



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## My Risk Factors Checklist (continued)

### Cervical Cancer (continued)

HIV infection

Weakened immune system due to such factors as an organ transplant, chemotherapy, or chronic corticosteroid use

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Extremely overweight (obese)

Diabetes

Heavy alcohol use

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Inactivity/lack of exercise

Overweight

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African American, American Indian, or Hispanic

### Obesity

Diet of high-calorie foods, such as fast foods, soft drinks, and sweets

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A medical condition that leads to decreased activity



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	Family history of osteoporosis
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	Had extended bed rest
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	Extended use of certain medicines (such as prednisone, cortisone, prednisolone, and dexamethasone)
	Small body frame/very thin
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	Male over age 50
	African-American male (Prostate cancer occurs almost 70 percent more often in black men than it does in white men.)
	Family history (in father or brother)
	High-fat diet
	Overweight

**High Cholesterol**

	Inactivity/lack of exercise
	Overweight
	High-fat, high-cholesterol diet
	Smoking
	Type 2 diabetes
	Family history of atherosclerosis (narrowing of the arteries)
	High blood pressure



## My Risk Factors Checklist (continued)

### High Blood Pressure

	Inactivity, lack of exercise
	Family history
	Age (90% of people who, at age 55, do not have hypertension will eventually develop it.)
	African American
	Heavy alcohol use
	Low intake of potassium, magnesium, and calcium
	Overweight/obese
	Smoking
	High sodium (salt) intake
	Sodium/salt sensitivity (People who are sodium sensitive retain sodium. This can lead to fluid retention and high blood pressure.)
	Low potassium intake
	High levels of stress can lead to temporary but striking increase in blood pressure.
	High blood cholesterol
	Diabetes
	Sleep apnea (breathing stops for short periods of time during sleep.)

<b>Routine Screening and Immunization Plan</b>				
	<b>Completed</b>	<b>Next Due Date</b>	<b>Completed</b>	<b>Next Due Date</b>
<b>Routine Preventive Screenings</b>				
Physical exam				
Blood pressure				
Height and weight				
Cholesterol check				
Colorectal cancer tests:				
Fecal occult blood test				
Flexible sigmoidoscopy				
Double-contrast barium enema				
Colonoscopy				
Bone-density test				
Blood sugar (glucose) test (for diabetes)				
<b>Immunizations</b>				
Flu				
Pneumonia/pneumococcal				
Tetanus/diphtheria				
Measles/mumps/rubella (MMR)				
Chickenpox				
Hepatitis A				
Hepatitis B				
<b>Women only!</b>				
Mammogram				
Clinical breast exam				
Pap test and pelvic exam				
<b>Men only!</b>				
Prostate cancer tests:				
Digital rectal exam				
Prostate specific antigen (PSA) test				
Urine test				



## **Notes**

<b>Routine Screening and Immunization Plan</b>				
	<b>Completed</b>	<b>Next Due Date</b>	<b>Completed</b>	<b>Next Due Date</b>
<b>Routine Preventive Screenings</b>				
Physical exam				
Blood pressure				
Height and weight				
Cholesterol check				
Colorectal cancer tests:				
Fecal occult blood test				
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Pneumonia/pneumococcal				
Tetanus/diphtheria				
Measles/mumps/rubella (MMR)				
Chickenpox				
Hepatitis A				
Hepatitis B				
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Mammogram				
Clinical breast exam				
Pap test and pelvic exam				
<b>Men only!</b>				
Prostate cancer tests:				
Digital rectal exam				
Prostate specific antigen (PSA) test				
Urine test				

## **Notes**



## Checklist for Planning Ahead if You Need Disability-Specific Assistance

✓	Check all items that apply to you:
	A support person who assists me will accompany me. However, I make my own decisions and want health providers to discuss my choices with me directly. Providers should speak directly to me rather than to or through my support person.
	I need providers to use “everyday” plain language and to pause often, to be sure that I am following what they are saying.
	I need providers to give me information that is clear and understandable.
	I need providers to use pictures or models. Sometimes I need them to demonstrate how to do something.
	I need to ask questions that are important to me, and I need providers to be patient when I am trying to understand new information.
	A slow response or lack of response does not necessarily mean I am not aware of what is being said. Providers should allow extra time for me to respond.
	I read lips and I need people to face me when speaking to me. Therefore:
	<ul style="list-style-type: none"> <li>• People should keep their hands away from their mouth when speaking.</li> </ul>
	<ul style="list-style-type: none"> <li>• People should use their normal tone of voice when talking with me.</li> </ul>
	<ul style="list-style-type: none"> <li>• People should raise their voice so I can hear what they are saying to me.</li> </ul>
	I am deaf and need to use an interpreter to sign conversations:
	<ul style="list-style-type: none"> <li>• American Sign Language (ASL)</li> </ul>
	<ul style="list-style-type: none"> <li>• Signed English</li> </ul>
	<ul style="list-style-type: none"> <li>• Oral</li> </ul>
	<ul style="list-style-type: none"> <li>• I will use a family member or friend.</li> </ul>
	<ul style="list-style-type: none"> <li>• The speaker should speak directly to me and not the interpreter.</li> </ul>
	<ul style="list-style-type: none"> <li>• Other:</li> </ul>
	I need to have consent forms and instructions read to me.
	I need consent forms and instructions provided in this format:
	<ul style="list-style-type: none"> <li>• Braille</li> </ul>
	<ul style="list-style-type: none"> <li>• Large print</li> </ul>
	<ul style="list-style-type: none"> <li>• Computer disk</li> </ul>
	<ul style="list-style-type: none"> <li>• Audio (tape, CD-ROM, MP3)</li> </ul>
	I need assistance in filling out forms.



## Checklist for Planning Ahead if You Need Disability-Specific Assistance (continued)

✓	Check all items that apply to you:
	I would like to have all forms I must complete sent to me before my appointment. I will read them, complete them, and bring them with me to the appointment.
	My speech is slow and/or difficult to understand.
	<ul style="list-style-type: none"> <li>• Please allow extra time so I can ask questions.</li> </ul>
	<ul style="list-style-type: none"> <li>• Please avoid acting as if you understand me, unless you do.</li> </ul>
	<ul style="list-style-type: none"> <li>• If what I say is not understood, ask me to repeat it, even three or four times, if needed.</li> </ul>
	If what I say is still not understood, ask me to:
	<ul style="list-style-type: none"> <li>• Use paper and pen.</li> </ul>
	<ul style="list-style-type: none"> <li>• Spell the words.</li> </ul>
	<ul style="list-style-type: none"> <li>• Other:</li> </ul>
	I use a communication device or a communication board.
	<ul style="list-style-type: none"> <li>• Please try not to interrupt or finish my sentences.</li> </ul>
	<ul style="list-style-type: none"> <li>• It is OK to interrupt or finish my sentences.</li> </ul>
	<ul style="list-style-type: none"> <li>• Please allow for extra time so I can ask questions.</li> </ul>
	<ul style="list-style-type: none"> <li>• Other:</li> </ul>
	I need to know if the building, office, exam rooms, scales and equipment are wheelchair-accessible.*
	<ul style="list-style-type: none"> <li>• I need a height-adjustable (high/low) exam table• and/or</li> </ul>
	<ul style="list-style-type: none"> <li>• I need help getting onto an exam table.*</li> </ul>
	I need to use a wheelchair-accessible restroom.*
	I need to take an accessible bus that has an accessible route from the bus stop to the office.*
	I need an accessible parking space and an accessible route (including an elevator if not on entry level) into the health provider’s office.*
	If I am referred to another provider (such as a specialist) for consultations, procedures, or tests, I need to be sure that the facilities and equipment are accessible and/or staff are willing and able to provide assistance with:
	<ul style="list-style-type: none"> <li>• Transfers</li> </ul>
	<ul style="list-style-type: none"> <li>• Positioning</li> </ul>
	<ul style="list-style-type: none"> <li>• Other:</li> </ul>



## Checklist for Planning Ahead if You Need Disability-Specific Assistance (continued)

	I use a service dog, so please alert anyone who is allergic to or frightened of dogs.*
✓	<b>Check <input type="checkbox"/> all items that apply to <input type="checkbox"/> you:</b>
	I have <input type="checkbox"/> life-threatening or <input type="checkbox"/> health-threatening reaction to:
	<ul style="list-style-type: none"> <li>• Latex</li> </ul>
	<ul style="list-style-type: none"> <li>• Pesticides</li> </ul>
	<ul style="list-style-type: none"> <li>• Roofing sealant</li> </ul>
	<ul style="list-style-type: none"> <li>• Paint</li> </ul>
	<ul style="list-style-type: none"> <li>• Scented personal care products</li> </ul>
	<ul style="list-style-type: none"> <li>• Other:</li> </ul>
	I will need to reschedule my appointment if I will be exposed to the above products.
My provider should consider developing a scent-free workplace policy.	
Sources:	
Kailes, J. (2002). <i>Preferred Practices to Keep in Mind as You Meet People with Disabilities</i> , Playa del Rey, CA : KAILES - Publications. Available at: <a href="http://www.jik.com/resource.html">www.jik.com/resource.html</a> or from <a href="mailto:jik@pacbell.net">jik@pacbell.net</a> .	
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## **Notes**



## Checklist for Planning Ahead if You Need Disability-Specific Assistance

✓	Check all items that apply to you:
	A support person who assists me will accompany me. However, I make my own decisions and want health providers to discuss my choices with me directly. Providers should speak directly to me rather than to or through my support person.
	I need providers to use “everyday” plain language and to pause often, to be sure that I am following what they are saying.
	I need providers to give me information that is clear and understandable.
	I need providers to use pictures or models. Sometimes I need them to demonstrate how to do something.
	I need to ask questions that are important to me, and I need providers to be patient when I am trying to understand new information.
	A slow response or lack of response does not necessarily mean I am not aware of what is being said. Providers should allow extra time for me to respond.
	I read lips and I need people to face me when speaking to me. Therefore:
	<ul style="list-style-type: none"> <li>• People should keep their hands away from their mouth when speaking.</li> </ul>
	<ul style="list-style-type: none"> <li>• People should use their normal tone of voice when talking with me.</li> </ul>
	<ul style="list-style-type: none"> <li>• People should raise their voice so I can hear what they are saying to me.</li> </ul>
	I am deaf and need to use an interpreter to sign conversations:
	<ul style="list-style-type: none"> <li>• American Sign Language (ASL)</li> </ul>
	<ul style="list-style-type: none"> <li>• Signed English</li> </ul>
	<ul style="list-style-type: none"> <li>• Oral</li> </ul>
	<ul style="list-style-type: none"> <li>• I will use a family member or friend.</li> </ul>
	<ul style="list-style-type: none"> <li>• The speaker should speak directly to me and not the interpreter.</li> </ul>
	<ul style="list-style-type: none"> <li>• Other:</li> </ul>
	I need to have consent forms and instructions read to me.
	I need consent forms and instructions provided in this format:
	<ul style="list-style-type: none"> <li>• Braille</li> </ul>
	<ul style="list-style-type: none"> <li>• Large print</li> </ul>
	<ul style="list-style-type: none"> <li>• Computer disk</li> </ul>
	<ul style="list-style-type: none"> <li>• Audio (tape, CD-ROM, MP3)</li> </ul>
	I need assistance in filling out forms.





## Checklist for Planning Ahead if You Need Disability-Specific Assistance (continued)

✓	Check all items that apply to you:
	I would like to have all forms I must complete sent to me before my appointment. I will read them, complete them, and bring them with me to the appointment.
	My speech is slow and/or difficult to understand.
	<ul style="list-style-type: none"> <li>• Please allow extra time so I can ask questions.</li> </ul>
	<ul style="list-style-type: none"> <li>• Please avoid acting as if you understand me, unless you do.</li> </ul>
	<ul style="list-style-type: none"> <li>• If what I say is not understood, ask me to repeat it, even three or four times, if needed.</li> </ul>
	If what I say is still not understood, ask me to:
	<ul style="list-style-type: none"> <li>• Use paper and pen.</li> </ul>
	<ul style="list-style-type: none"> <li>• Spell the words.</li> </ul>
	<ul style="list-style-type: none"> <li>• Other:</li> </ul>
	I use a communication device or a communication board.
	<ul style="list-style-type: none"> <li>• Please try not to interrupt or finish my sentences.</li> </ul>
	<ul style="list-style-type: none"> <li>• It is OK to interrupt or finish my sentences.</li> </ul>
	<ul style="list-style-type: none"> <li>• Please allow for extra time so I can ask questions.</li> </ul>
	<ul style="list-style-type: none"> <li>• Other:</li> </ul>
	I need to know if the building, office, exam rooms, scales and equipment are wheelchair-accessible.*
	<ul style="list-style-type: none"> <li>• I need a height-adjustable (high/low) exam table• and/or</li> </ul>
	<ul style="list-style-type: none"> <li>• I need help getting onto an exam table.*</li> </ul>
	I need to use a wheelchair-accessible restroom.*
	I need to take an accessible bus that has an accessible route from the bus stop to the office.*
	I need an accessible parking space and an accessible route (including an elevator if not on entry level) into the health provider’s office.*
	If I am referred to another provider (such as a specialist) for consultations, procedures, or tests, I need to be sure that the facilities and equipment are accessible and/or staff are willing and able to provide assistance with:
	<ul style="list-style-type: none"> <li>• Transfers</li> </ul>
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	<ul style="list-style-type: none"> <li>• Other:</li> </ul>



## Checklist for Planning Ahead if You Need Disability-Specific Assistance (continued)

	I use a service dog, so please alert anyone who is allergic to or frightened of dogs.*
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	<ul style="list-style-type: none"> <li>• Latex</li> </ul>
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## **Notes**

Test Result Communication Form		
Please send my test results to:		
<b>Patient*:</b>		
Address		
City	State	Zip
Phone:	Fax:	
<b>Primary Care Provider:</b>		
Address		
City	State	Zip
Phone:	Fax:	
<b>Provider:</b>		
Address		
City	State	Zip
Phone:	Fax:	
<b>Provider:</b>		
Address		
City	State	Zip
Phone:	Fax:	
<b>Provider:</b>		
Address		
City	State	Zip
Phone:	Fax:	
<b>Provider:</b>		
Address		
City	State	Zip
Phone:	Fax:	
<b>Comments:</b>		

\*Always include yourself on the lists of individuals who are to receive your test results.

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<b>Provider:</b>		
Address		
City	State	Zip
Phone:	Fax:	
<b>Provider:</b>		
Address		
City	State	Zip
Phone:	Fax:	
<b>Provider:</b>		
Address		
City	State	Zip
Phone:	Fax:	
<b>Provider:</b>		
Address		
City	State	Zip
Phone:	Fax:	
<b>Comments:</b>		

\*Always include yourself on the lists of individuals who are to receive your test results.

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## **Notes**

## **Routine Preventive Screening for People with Physical Disabilities: Tips for Health Care Providers**

**By June Isaacson Kailes**

**Associate Director, Center for Disability Issues and the Health Professions  
Western University of Health Sciences  
Pomona, California**

### **The Importance of Preventive Screening for People with Disabilities**

People with disabilities have health promotion and disease prevention needs equal to, and sometimes greater than, those of people without disabilities. However, many people with disabilities do not get routine preventive screenings and other important health promotion and disease prevention services. At the same time, people with physical impairments may face increased risks for conditions such as obesity, diabetes, heart and cardiovascular disease, and some cancers because of inactive lifestyles, lack of exercise, and physiological changes associated with disability. For example:

- ◆ In the United States, people with disabling conditions have three to four times as many health problems as people without disabilities. The most common health conditions among people with disabilities include hypertension, diabetes, high

cholesterol, obesity, and osteoporosis.<sup>3</sup>

- ◆ Some medical conditions appear to be strongly linked to the primary disabling condition. For instance:
  - People with spinal cord injury develop diabetes at nearly four times the rate of people without disabilities.
  - One of the leading causes of death among people with spinal cord injury is cardiovascular disease.
  - People with cerebral palsy have many more fractures per year than people their age without disabilities.
  - People with limited mobility often have low bone density (some may need to pursue screening for low bone density at age 35 instead of waiting until age 65).
- ◆ People with limited mobility (for example, those with spinal cord injury, cerebral palsy, and post-polio



## Making Preventive Health Care Work for You – *A Resource Guide for People with Physical Disabilities*



syndrome) can experience certain medical conditions earlier than non-disabled people of the same age.

- ◆ For reasons still not well understood, individuals with disabling conditions are also at greater risk of new medical problems as they get older<sup>1</sup>.

Lack of health promotion and disease prevention activities specific to people with disabilities may further exacerbate the occurrence of secondary conditions within this population.

All of these facts point to the vital need for people with disabilities to get routine preventive screenings at the appropriate time. They also suggest the importance of customized exercise programs and weight-loss strategies for people with disabilities. In fact, these health promotion services could be more valuable for people with

disabilities than for others because of their potentially greater beneficial impact within this population.

Encouraging routine preventive health screening is especially important for people with physical disabilities because they may have:

- ◆ Greater risks for acquiring preventable health conditions (such as high blood pressure, diabetes, and osteoporosis), compared to the general population.
- ◆ Less access to and lower rates of routine screening, compared to the general population.
- ◆ Difficulty getting to health care providers' offices because of issues related to transportation (e.g., not having accessible, reliable, and safe transportation) and because of inadequate building and office equipment accessibility.
- ◆ Health care providers who lack disability-specific experience; mistakenly believe that many specific health problems result from the disability; and often do not address general, sexual, diet, and physical activity issues because they focus only on the disability.

### **Ways to Increase Routine Preventive Screening among People with Disabilities**

Problems such as lack of adequate transportation, inaccessible offices and equipment, and attitudinal barriers may prevent people with disabilities from visiting their doctors and other health care providers to get needed services. Improving physical access and accommodations, increasing “disability literacy,” and developing disability competency can make it easier for people with disabilities to receive routine preventive screenings. These goals are briefly discussed below.

#### **Improve Your Office’s Physical Access**

In order to receive high-quality routine preventive screenings, people with physical disabilities and activity limitations often must get physical, equipment, procedural, and scheduling accessibility and accommodations. Accessibility problems may include transportation problems, barriers getting into the building or offices (e.g., lack of ramps or accessible doorways), and lack of equipment such as exam tables or imaging machines that can be used by people with disabilities.

The Resources section below lists products to assist health care providers in improving accessibility for people with disabilities.

### **Increase Your Disability Literacy**

Health care providers can take steps to increase their own and office staff’s disability literacy. Disability literacy includes understanding:

- ◆ Different kinds of disabilities and activity limitations
- ◆ The importance of being sensitive to the needs of people with disabilities and of interacting effectively and respectfully with individuals with diverse disabilities
- ◆ Legal obligations in complying with the Americans with Disabilities Act (ADA) and other laws so that people with disabilities receive the same quality of health care as that provided to people without disabilities
- ◆ The need to develop and implement office procedures and policies to accommodate people with disabilities
- ◆ How to assess personal prejudices, stereotypes, and biases, and how to overcome them or prevent them from emerging when working with people with disabilities. It is common for people to unknowingly demonstrate bias through their behavior and language. To eliminate bias:
  - Don’t assume that health, wellness, and disability cannot coexist. Physical decline, illness, and other

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conditions (often referred to as secondary conditions) need not accompany living with a disability.

- Don't focus only on an individual's disability. When health care providers focus on the disability, they may overlook routine screenings that help prevent major illnesses.<sup>3</sup>
- Don't skip asking about diet, birth control, smoking, drug use, heavy alcohol use, unprotected sex, sexually transmitted diseases, etc. These issues are as important to people with disabilities as they are to other people.
- Don't assume that the more severe a disability, the less an individual's quality of life.
- Don't assume that anyone with a significant disability is depressed.
- Don't assume that people with disabilities do not know about their

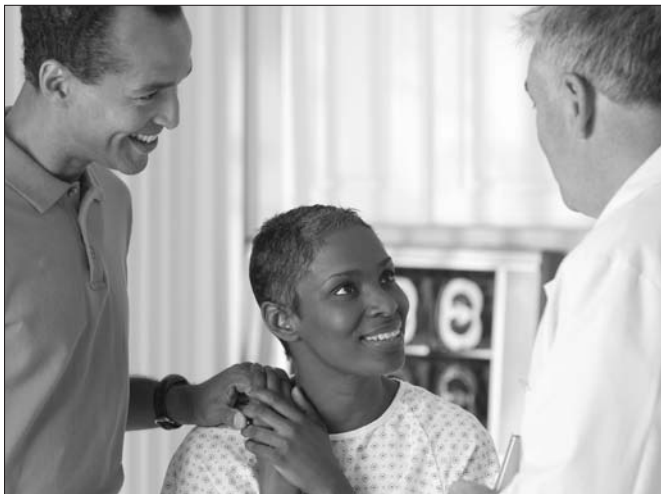
disability. Treat people as partners in the health care decision-making process.

- Respect the expertise of people who have lived with their disabilities and unique health care needs. Many individuals have sophisticated knowledge about their own bodies and selected approaches to their health management.

### Develop Your Disability Competence

In addition to developing disability literacy, it is important to strengthen your own and your office staff's disability competence. Disability competence includes:

- ◆ Existence of a set of compatible behaviors, beliefs, attitudes, values, practices, skills, and policies. These elements enable a system, organization, or provider to work effectively with a diverse population of people who have disabilities or activity limitations<sup>2</sup>. The elements are continually reinforced through internal evaluation and ongoing education.
- ◆ Knowledge about how to effectively offer accessible programs and services that accommodate and are inclusive of people with disabilities.
- ◆ Understanding and willingness to follow disability-sensitive etiquette, protocols, policies, and procedures.



## **Useful Resources**

### **Accessible Health Care Series**

[www.cdihp.org/products.html](http://www.cdihp.org/products.html)

This series offers information about improving access to health care services, programs, and products. Topics include:

- ◆ Importance of Accessible Examination Tables
- ◆ Importance of Accessible Weight Scales
- ◆ Tax Incentives for Improving Accessibility
- ◆ Health Care Facilities Access
- ◆ ADA Resources
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- ◆ Choosing and Negotiating an Accessible Business Location
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### **Health, Wellness and Aging with Disability Resources**

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## **References**

1. Kemp, B. (2001). Aging with a disability: What's been learned? *Orchid: Health and Wellness for women with disabilities, Summer Edition*, NCODH, CB#8185, UNC-CH, Chapel Hill, NC 27599-8185, <http://www.fpg.unc.edu/~ncodh/WomensHealth/Womenshealthpub.htm>
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- ◆ The need to develop and implement office procedures and policies to accommodate people with disabilities
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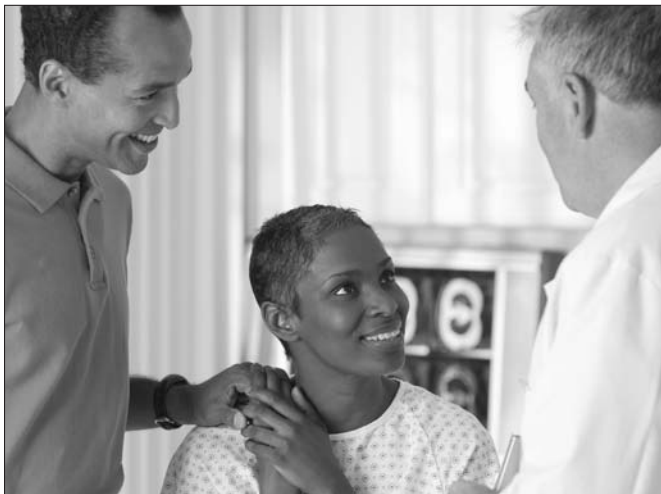
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- ◆ Tax Incentives for Hiring People with Disabilities

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## **Notes**

## Please Tell Us What You Think

Answer these questions, remove the page and mail – no postage is needed!

Please answer the questions below: (please check one box for each statement)	No, Not at All	Somewhat	Yes, Very much
1. Did this guide help you understand the questions that you need to ask your doctor?			
2. Did this guide help you understand your risk factors?			
3. Did this guide help you to know what to expect for routine screening?			
4. Did this guide help you become more active in seeking routine screening?			
5. Did this guide prepare you for visits with your providers?			
6. Did this guide help you communicate with your providers?			
7. Did this guide help you plan for when you need assistance?			
8. Did this guide help you improve the way you spend time during your visit with your doctor?			
9. Did this guide help you to remember what your doctors tell you?			
10. Did this guide help you get your test results?			
11. Did this guide help you get your test results to your other health care providers?			
12. The information was: <input type="checkbox"/> Easy to understand <input type="checkbox"/> Hard to understand			
13. The information was: <input type="checkbox"/> Too much <input type="checkbox"/> Too little <input type="checkbox"/> Just the right amount			
14. More information should be given about: _____			
_____			
15. Less information should be given about: _____			
_____			
16. Did you share "Tips for Health Care Providers" with your providers? <input type="checkbox"/> Yes <input type="checkbox"/> No			
Comments _____			
17. I would recommend this guide to another person with a physical disability: <input type="checkbox"/> Yes <input type="checkbox"/> No			
18. I received this guide from: <input type="checkbox"/> A disability-related organization <input type="checkbox"/> A family member or friend			
<input type="checkbox"/> Center for Disability Issues and the Health Professions <input type="checkbox"/> Other (please explain): _____			
19. I am a (check all that apply): <input type="checkbox"/> Person with a disability or activity limitation			
<input type="checkbox"/> Service professional <input type="checkbox"/> Other (please explain): _____			
20. How far did you go in school? <input type="checkbox"/> 8th grade or less <input type="checkbox"/> Some high school			
<input type="checkbox"/> High school graduate <input type="checkbox"/> Some college <input type="checkbox"/> College graduate <input type="checkbox"/> Graduate school			

23. How did you or how do you plan to use this information? \_\_\_\_\_

Other comments: \_\_\_\_\_

**Optional**

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Phone number: \_\_\_\_\_ Fax number: \_\_\_\_\_

E-mail address: \_\_\_\_\_

May we quote you?  Yes  No



**FOLD**

**Tape here to seal**

**FOLD**

Return address

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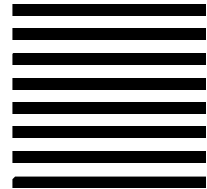


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# How To Make Preventive Health Care Work For You

It is important to understand your risk of developing health problems. It is also important to get preventive care to stay healthy. Often, though, people with disabilities don't get the kinds of preventive health services they need.

## Do you. . .

- ◆ Put off getting medical checkups because it's hard to get to the doctor's office or because the office staff does not try to meet your needs?
- ◆ Think that regular checkups aren't really important because of your disability?
- ◆ Feel frustrated because your doctor doesn't answer your questions or discuss your health concerns like weight loss, smoking, birth control, or sexually transmitted diseases?
- ◆ Want to know how to feel less anxious or nervous when talking with health care providers?
- ◆ Feel that you're not getting the right routine preventive screenings?

## If you answered yes, you're not alone!

This Resource Guide helps people with physical disabilities take steps to make preventive health care work for them. Designed with input from both consumers and health care providers, this Guide offers important information, tools, and resources to help you:

- Determine your health risks
- Learn why routine preventive screenings and vaccines are important
- Create a Routine Screening and Immunization Plan tailored to your own needs
- Learn ways to become more active in your health care
- Increase your confidence and improve your communication skills to work more effectively with health care providers



Use the Resource Guide as a planning guide or a reference to start making preventive health services work better for you!