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Transition Outreach Training for Adult Living (TOTAL) Project

Module 9

Health and Medical Issues in Transition Planning

Module 9, Health and Medical Issues in Transition Planning, has been developed to increase awareness and knowledge of transition-related medical issues for individuals with chronic health conditions/disabilities. Health care transition planning is discussed in the areas of independent living, college and employment.



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TOTAL Project, 2005

Transition Outreach Training for Adult Living Health and Medical Issues in Transition Planning

Objective

The purpose of this training is to increase awareness and knowledge of transition-related medical issues for individuals with chronic health conditions/disabilities. Health care transition planning will be discussed in the areas of independent living, college and employment.

Key Learning

At the end of the module, participants should be able to:

- Recognize laws that provide protection for individuals with disabilities and know resources to gain further information on their rights.
- Gain understanding of disclosure issues
- Understand ways to stay healthy
- Increase awareness of health care planning issues as a part of the transition plan to independent living.
- Increase awareness of differences between secondary and postsecondary education systems, along with ways to improve access to increase participation and achievement among individuals with chronic health conditions/disabilities.
- Gain understanding of employment planning issues for people with disabilities, addressing health care needs and accommodations.

Materials

- Resources/Readings (may also be copied to hand out at the discretion of the trainer)
- Trainer note pages with slides
- Handouts for training participants
 - Slide handout pages for note-taking
 - Health Care Checklist
 - Emergency Evacuation Preparedness, Taking Responsibility for your Safety, A Guide for People with Disabilities and Other Activity Learning Limitations
 - HRTW Tools and Tips: Public and Private Insurance Plans: Understanding the Options for YSHCN
 - Creating Accessible Homes
 - What to Ask When Visiting the Office of Disabilities
 - HRTW Tools and Tips: Work and You: Your Special Health Care Needs in the Workplace

Trainer Preparation

1. Review trainer reading
2. Review trainer note pages and handouts
3. Duplicate handouts

Training Guide

1. Introduce the training topic and learning objectives.
2. Present the training with corresponding handouts by following the trainer notes pages.
3. Conclude by disseminating and collecting workshop evaluation forms.

Curriculum Resources

Adolescent Autonomy Checklists. Adolescent Health Transition Project (AHTP) Children with Special Health Care Needs Program, PO Box 47880, Olympia, WA 98504-7880 Retrieved from the World Wide Web: <http://depts.washington.edu/healthtr/Checklists/intro.htm>

Bode, Marilyn, *Creating Accessible Homes*, Extension Housing Specialist, Department of Apparel, Textiles, and Interior Design, Kansas State University. Retrieved from the World Wide Web: <http://www.oznet.ksu.edu/library/HOUS2/MF2213.pdf>.

Buchanan, Laverne A., (2002). *The Disclosure Dilemma for Advocates.* HEATH Resource Center, George Washington University. Retrieved from the World Wide Web: <http://www.heath.gwu.edu/PDFs/Disclosure%20Dilemma.pdf>

Census Data for Persons with Disabilities. (2003). American Association of People with Disabilities, Washington, D.C. Retrieved from the World Wide Web: <http://www.aapd.com/News/disability/2003censusdata.html>.

Crockett, E. (2001). *Toto, I Have a Feeling We're Not in School Anymore*, University of Montana-Missoula. Retrieved from the World Wide Web: <http://www.umt.edu/dss/trans/toto-01.html>

Directing Care & Asking for Assistance: Louisiana Statewide Transition Project and Louisiana: Healthy and Ready to Work Fact Sheet Series. Retrieved from the World Wide Web: <http://www.hdc.lsuhs.edu/Programs/as/Fact%20Sheets/Directing%20Care%20&%20Asking%20for%20Assistance.html>.

Edelman, A., Schuyler, B., White, P. *Maximizing Success for Young Adults with Chronic Health-Related Illnesses.* HEATH Resource Center, George Washington University, Washington, DC.

Gibson, Robert. (December 2003). *The Consortium Consumer Brief: Promising Practices in Health Care Transition: A Research Fact Sheet for Consumers.* National Institute on Disability and Rehabilitation Research of the U.S. Department of Education. Retrieved from the World Wide Web: http://hctransitions.ichp.edu/pdfs/ConsBrief_1203Final.pdf.

Health Care Checklist. University of Illinois at Chicago: Division of Specialized Care for Children, Springfield, Illinois. Retrieved from the World Wide Web:
<http://internet.dsc.uic.edu/forms/psu/4202.pdf>.

National Collaborative for Workforce and Disability for Youth. (2004) *Disclosure Workbook*. Washington, D.C: U.S. Government Printing Office.

Johnson, M., Duncan, R., Gabriel, A., & Carter, Michael (1999). *Home Modifications and Products for Safety and Ease of Use*. The Center for Universal Design. Retrieved from the World Wide Web: http://www.design.ncsu.edu/cud/built_env/housing/article_hmod.htm.

Kailes, June I. (2002). *Emergency Evacuation Preparedness: Taking Responsibility for Your Safety: A Guide For People With Disabilities and Other Activity Limitations*, Published and distributed by Center for Disability Issues and the Health Professions, Western University of Health Sciences, 309 E Second Street, Pomona, CA 91766-1854, Voice: 909) 469-5380, TTY: (909) 469-5520, Fax: (909) 469-5407, Email: evac@westernu.edu. Retrieved from the World Wide Web: <http://www.cdihp.org/products.html>
http://www.cdihp.org/evacuation/emergency_evacuation.pdf.

Moving Towards More Health and Medical Independence: Adolescence: Louisiana Statewide Transition Project and Louisiana: Healthy and Ready to Work Fact Sheet Series. Retrieved from the World Wide Web:
<http://www.hdc.lsuhs.edu/Programs/as/Fact%20Sheets/moving%20towards%20more%20independence%20fact%20sheet.htm>.

Peterson, K. (2004). *Supporting the Dynamic Development of Youth with Disabilities During Transition: A Guide for Families*. Louisiana – Healthy and Ready to Work. Retrieved from the World Wide Web: <http://www.ncset.org/publications/default.asp>.

Public And Private Insurance Plans: Understanding the Options for Youth with Special Health Care Needs. Healthy Ready to Work (HRTW) Tools and Tips. Retrieved from the World Wide Web: http://www.hrtw.org/healthcare/hlth_ins.html.

Secondary School Programming for Students Not Heading to College. Sevier County Board of Education, Sevierville, TN. Retrieved from the World Wide Web:
<http://www.slc.sevier.org/secprog.htm>.

The ADA: Your Employment Rights as an Individual With a Disability. U.S. Equal Employment Opportunity Commission, Washington, D.C. Retrieved from the World Wide Web:
<http://www.eeoc.gov/facts/ada18.html>.

The New Freedom Initiative's Online Resource for Persons with Disabilities. Washington, D.C. Retrieved from the World Wide Web:
<http://www.disabilityinfo.gov/digov-public/public/DisplayPage.do%3fparentFolderId=500>.

What is School to Work? Lincoln Land School to Work Partnership, Springfield, IL
Retrieved from the World Wide Web: <http://www.llcc.cc.il.us/stw/WhatIsSTW.htm>.

Transition Outreach Training for Adult Living



**Health and Medical Issues
in Transition Planning**

IDEA 2004

Federal Definition of Transition

a) Transition services means a **coordinated set of activities** for a child with a disability that:

1. is **designed within a results-oriented process**, that is focused on improving the academic and functional achievement of the child with a disability to facilitate movement from school to post school activities, including post-secondary education, vocational education, integrated employment, continuing and adult education, adult services, independent living or community participation...

(IDEA 2004, 602(34)(A))

Beginning no later than the first IEP to be in effect when the child is 16 . . .

- each student must have included in the IEP appropriate measurable post-secondary goals based on age appropriate transition assessments related to:
 - training,
 - education,
 - employment, and, where appropriate
 - independent living skills.

Transition Services

Transition-Related Medical Issues

– Addressing health and its impact

- Independent Living

- College

- Work

New Freedom Initiative



- Increases access to assistive and universally designed technologies;
- Expands educational opportunities;
- Promotes homeownership;
- Integrates Americans with disabilities into the workforce;
- Expands transportation options; and
- Promotes full access to community life.

<http://www.os.dhhs.gov/newfreedom/>

Information is Power!

An individual can ultimately enjoy greater control over his/her circumstances when he/she is empowered:

- **To know their rights under the laws**
- **To disclose information**
- **To know ways to stay healthy**
- **To be part of the community**
- **To access appropriate education**
- **To gain employment**

Laws

<p>Individuals with Disabilities Educational Act (2004) (IDEA)</p> <p>http://www.federalresourcecenter.org/frc/idea.htm</p>	<p>Technology-Related Assistance (100-407) (103-218)</p> <p>http://www.resna.org/taproject/library/laws/techact94.htm</p>	<p>Carl D. Perkins Vocational Act (101-332)</p> <p>http://www.ed.gov/offices/OVAE/CTE/legis.html</p>
<p>Rehabilitation Act (1998)</p> <p>http://www.rcep7.org/links/rehabact/Index/index.html</p>	<p>Americans with Disabilities Act</p> <p>http://www.usdoj.gov/crt/ada/ada.htm</p>	<p>Workforce Investment Act (1998)</p> <p>http://www.isbe.state.il.us/partnerships/WIA1998.htm</p>
<p>Fair Housing Law</p> <p>http://www.hud.gov/offices/ftheo/FHLaws/index.cfm</p>	<p>HIPAA (1996)</p> <p>http://www.hhs.gov/ocr/hipaa/</p>	<p>Human Rights Act</p> <p>www.idhr1.com</p>

Disclosure

- Where to disclose?
 - A private setting
 - A place where only the intended recipient of the information will be informed

Disclosure

Why to disclose at work?

- Need accommodation
- Legal reasons
- Pending background check
- Safety or other health related reasons

When to disclose at work?

- Confidentiality is assured
- During application
- During interview
- Anytime after employment
- Never

What to disclose at work?

- Depends primarily on the purpose of the disclosure

Who to tell at work?

- Anyone directly providing accommodations
- Anyone in a position to support the request for accommodations
- Anyone who is responsible for evaluating performance
- Anyone responsible for health and safety

Disclosure

What to disclose in social settings?

- General information about the disability and the impact on social life & community
- What accommodations have worked
- Accent on positive contributions made in the community

Who to tell in social settings?

- Friends, acquaintances, relatives, staff of various businesses,
- Public transportation and parks/recreation staff, events coordinator

Why to disclose in social settings?

- To fully participate in what the community has to offer
- Start new relationships with honesty
- Identify and receive any necessary assistance

When to disclose in social settings?

- Prior to joining
- At the time of joining
- When involved
- When meeting new people
- Never

Staying Healthy

- Physical Care
 - Taking care of the body
- Mental Care
 - Liking oneself, focusing on positive feelings
- Social Care
 - Getting along with others



Health Care Management

- Medications
- Healthy diet
- Exercise
- Adequate sleep
- Personal care
- Sexuality
- Mental health



Health Care Management

Health Care Checklist

- Self-advocacy
- Chronic condition/disability
- Symptoms requiring medical attention
- Medical emergencies
- Medical appointments/Medical history
- Medications



Health Care Management

Health Care Checklist

- Refills/supplies
- Daily treatments
- General health maintenance (exercise, good eating habits, hygiene...)
- Transportation to medical office
- Adult care physician



Health Care Coverage

Know health care coverage by name and carry insurance card.

- Parents' coverage: Check eligibility requirements before turning 18
- Health insurance through employment
- College student low-cost insurance plan
- Health Benefits for Workers with Disabilities
<http://www.hbwdillinois.com/>
- Medicaid <http://www.dpailinois.com/medical/>

Students With Special Health Care Needs Transition to Independent Living

- Independent Living Skills
 - Time management
 - Energy management
 - Handling money
 - Stress management and coping skills
 - Be an assertive, effective advocate
 - Self-care skills for daily living
 - Health and wellness care
 - Accessing information and resources

Adolescent Autonomy Checklist:

<http://depts.washington.edu/healthtr/Checklists/intro.htm>

Independent Living

Modifications and Accommodations

Home Modifications for Safety and Ease of Use

http://www.design.ncsu.edu/cud/built_env/housing/article_hmod.htm

- Supports and assistive devices needed to perform
 - Activities of daily living skills
 - Home management tasks such as meal preparation, cleaning, laundry, grocery shopping....

Creating Accessible Homes Checklist

http://www.oznet.ksu.edu/johnson/FACS/Youth_Fam_Comm/YFCpg3.htm

- Looking at activity areas for eating, sleeping, bathing, lighting, flooring and telephone accessibility

Students With Special Health Care Needs Transition to Postsecondary Education

- Consider schools that have accessible programs and services
- Learn about each schools' Office of Disability Services
- When visiting schools, consider campus mobility, layout, location of facilities and distance to and from classes, and parking

Choosing A College

Locate the Office of Disability Services

- Be able to state the disability and its affects
- Know what accommodations and technology are needed
- Have documentation identifying the need for support services

Choosing A College

Locate Other Resources

- **Find the Student Health Center**
 - Speak with the Nurse
 - Give the Nurse a summary of health needs
- **Know the health care coverage by name and carry the insurance card**
- **Talk about a plan – discuss risks and benefits**
 - Primary care physician/specialist
 - Discuss times of illness
 - Nearby health care professionals
 - Special diets and contacting the director of food services
- **Prepare an emergency plan**

Choosing A College

Set Up Housing Accommodations

- **Call the Housing Office or Physical Plant**
 - Discuss necessary accommodations
 - Is a single room needed?
 - Does it need to be on the first floor?
 - Does it need air-conditioning?
 - Create an evacuation plan.

Choosing A College

Live Strong: Stay Healthy

Get a Pre-College Physical

- Immunizations, TB test, Meningitis, MMR, DT, Hepatitis, Influenza

Exercise

- Keep up with daily routines to the extent of abilities
- Improve endurance and stamina

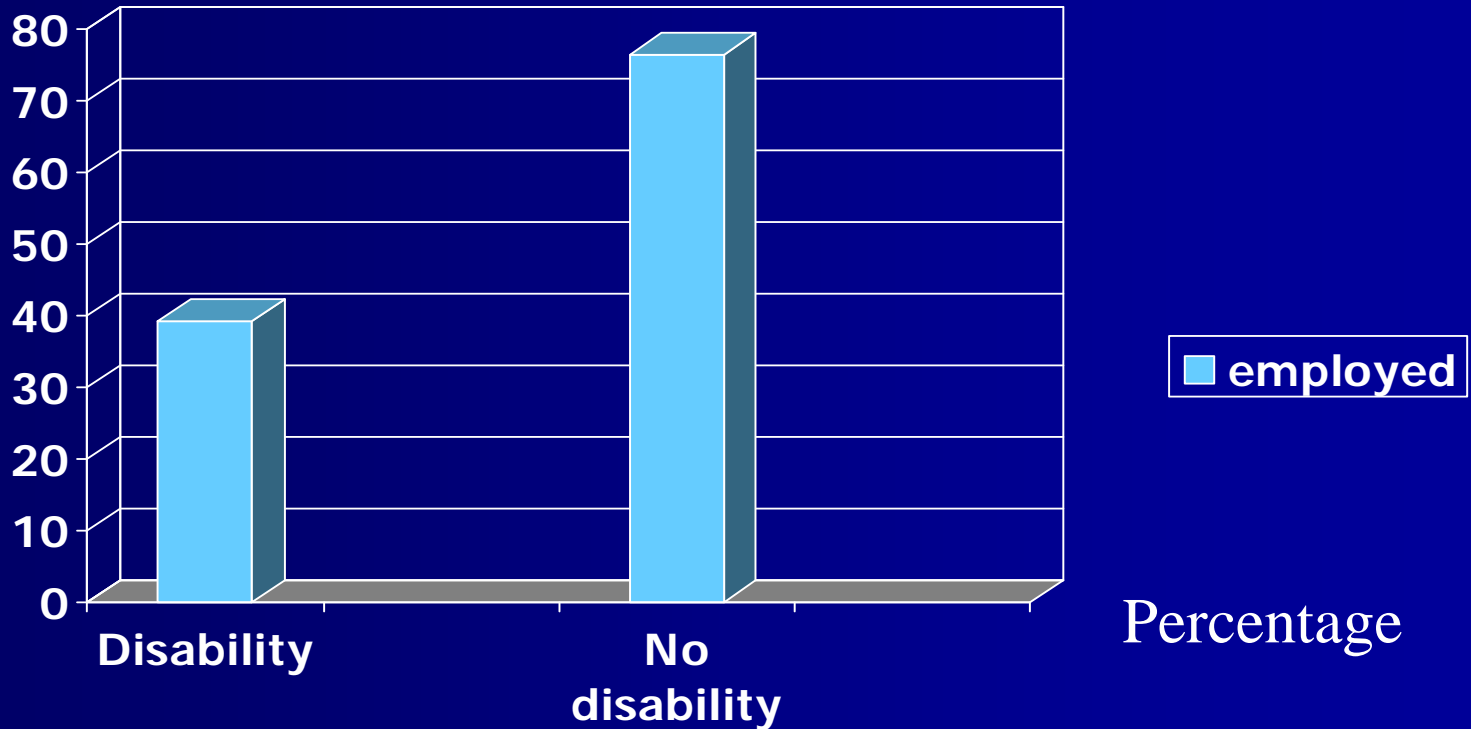
Choosing A College

Enhance Success

- **Select classes at the best time of day for stamina**
- **Arrive at class on time**
 - **Realize it may take longer to get there**
 - **Take all materials needed**
- **Hire a Personal Assistant, if needed**
- **Sit in the part of the room that fits health and learning needs**
- **Use assistive technology, if needed**

Employment Issues

2003 U.S. Census Report



Percentage

Students With Special Health Care Needs

Transition from School to Work

- Explore interests
- Get job experiences early
- Perform volunteer work for valuable experience
- Learn about employment related services
 - Division of Rehabilitation
 - Work incentive programs: PASS, Ticket to Work
 - Illinois Employment Training Centers



Choosing Employment

Vocational Training Goals

- | | |
|---|---|
| <ul style="list-style-type: none">■ Identify personal abilities■ Develop individual areas of interest■ Learn to compensate for personal limitations■ Learn to control emotional responses■ Develop occupational awareness | <ul style="list-style-type: none">■ Develop positive self-image■ Develop acceptable standards of dress and appearance■ Develop an awareness of social interactions■ Understand others■ Adjust behavior to setting■ Secure Employment |
|---|---|

Choosing Employment

Reasonable Accommodations

- | | |
|---|--|
| <ul style="list-style-type: none">■ Technology■ Software■ Personal attendant■ Accommodations not so high tech, like handles, space, time increments■ Restructuring jobs | <ul style="list-style-type: none">■ Modifying workstation■ Modifying restroom■ Modifying equipment■ Allowing interpreters and readers■ TTY, Braille■ Time off for treatment of a disability |
|---|--|

Health Care Needs in the Workplace

- Work environment
- Medical appointments
- Health routines
- Emergency plan
- Accommodations & supports



Healthy & Ready to Work

Choosing Employment Resources

- **A Guide to Disability Rights Laws**

U.W. Dept. of Justice Rights Division

Contact: (800)669-3362 or (800)800-3302 TTY

www.eeoc.gov

- **Job Accommodation Network**

Contact: 1-800-526-7234 TTY/Voice

<http://www.jan.wvu.edu/>

Choosing Employment Resources

- [U.S. Dept of Education ADA Help Line](#)

Contact: 1-800-949-4232

- [U.S. Dept of Education, Office of Civil Rights](#)

<http://www.ed.gov/about/offices/list/ocr/index.html>

- [Division of Rehabilitation Services](#)

<http://www.dhs.state.il.us/ors/>

Choosing Employment Resources

- **Illinois Employment & Training Centers**

<http://www.ides.state.il.us/ietc/map.asp>

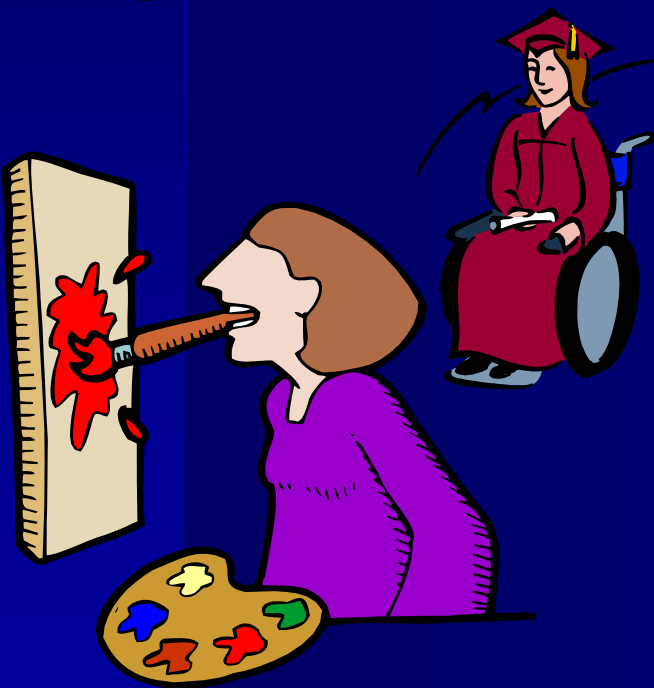
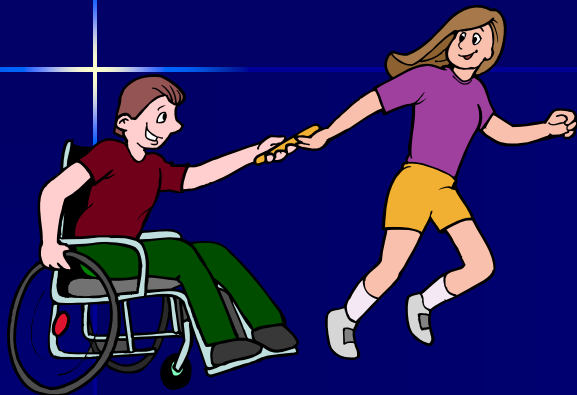
- **A Guide for People with Disabilities Seeking Employment**

<http://www.usdoj.gov/crt/ada/workta.htm>

- **Division of Specialized Care for Children (DSCC) Web Resources (Under Links)**

<http://www.uic.edu/hsc/dsc>

Health impacts all areas of life!



The Department of Labor's Employee Benefits Security Administration (EBSA) administers several important health benefit laws covering employer-based health plans. They govern your basic rights to information about how your health plan works, how to qualify for benefits, and how to make claims for benefits. In addition, there are specific laws protecting your right to health benefits when you lose coverage or change jobs. EBSA oversees health care laws covering special medical conditions. For more information on the laws that protect your benefits, see EBSA's Web site at www.dol.gov/ebsa. Or, call the agency's toll-free help line at 1-866-444-3272 to reach a regional office near you. These 10 tips can help make your health benefits work better for you.

These laws can help:

The Employee Retirement Income Security Act — Offers protections for individuals enrolled in pension, health, and other benefit plans sponsored by private-sector employers, provides rights to information, and a grievance and appeals process for participants to get benefits from their plans.

The Consolidated Omnibus Budget Reconciliation Act — Contains provisions giving certain former employees, retirees, spouses, and dependent children the right to purchase temporary continuation of group health plan coverage at group rates in specific instances.

The Health Insurance Portability and Accountability Act — Includes protections for millions of working Americans and their families who have preexisting medical conditions, prohibits discrimination in health care coverage, and guarantees issuance of individual policies for certain eligible individuals.

The Newborns' and Mothers' Health Protection Act — Provides rules on minimum coverage for hospital lengths of stay following childbirth.

Mental Health Parity Act — Requires that annual or lifetime dollar limits on mental health benefits be no lower than those dollar limits for medical and surgical benefits offered by a group health plan.

Women's Health and Cancer Rights Act — Offers protections for breast cancer patients who elect breast reconstruction in connection with a mastectomy.

To find out more ...

Call EBSA toll-free at **1-866-444-3272** for copies of the following brochures, or view them on the Internet at: www.dol.gov/ebsa.

- *Health Coverage Portability*
- *An Employee's Guide to Health Benefits Under COBRA*
- *Pension and Health Care Coverage...Questions and Answers for Dislocated Workers*
- *Can the Retiree Health Benefits Provided by Your Employer Be Cut?*

Also, visit the Centers for Medicare and Medicaid Services of the Department of Health and Human Services at www.cms.hhs.gov. Or, contact your State Insurance Commissioner's office.



Top 10 Ways To Make Your Health Benefits Work for You

U.S. Department of Labor

1 Your options are important. There are many different types of health benefit plans. Find out which ones your employer offers, then check out each plan. Your employer's human resource office, the health plan administrator, or your union can provide information to help you match your needs and preferences with the available plans. *The more information you have, the better your health care decisions will be.*

2 Reviewing the benefits available. Do the plans offered cover preventive care, well-baby care, vision or dental care? Are there deductibles? Answers to these questions can help determine the out-of-pocket expenses you may face. *Matching your needs and those of your family members will result in the best possible benefits. Cheapest may not always be best. Your goal is high quality health benefits.*

3 Look for Quality. The quality of health care services varies, but it can be measured. You should consider the quality of health care in deciding among the health care plans or options available to you. Not all health plans, doctors, hospitals, and other providers give the highest quality care. Fortunately, there is information you can use right now to help you compare your health care choices. *Find out how you can measure quality. Consult the U.S. Department of Health and Human Services publication Your Guide to Choosing Quality Health Care on the Web at www.ahrq.gov/consumer/qntool.htm.*

4 Your plan's summary plan description (SPD) provides a wealth of information. Your health plan administrator should provide a copy. It outlines your benefits and your legal rights under the Employee Retirement Income Security Act (ERISA), the federal law that protects your health benefits. It should contain information about the coverage of dependents, what services will require a co-pay, and the circumstances under which your employer can change or terminate a health benefits plan. *Save the SPD and all other health plan brochures and documents, along with memos or correspondence from your employer relating to health benefits.*

5 Assess your benefit coverage as your family status changes. Marriage, divorce, child birth or adoption, or the death of a spouse are life events that may signal a need to change your health benefits. You, your spouse, and dependent children may be eligible for a special enrollment period under provisions of the Health Insurance Portability and Accountability Act (HIPAA). Even without life-changing events, the information provided by your employer should tell you how you can change benefits or switch plans, if more than one plan is offered. A special note: If your spouse's employer also offers a health benefits package, consider coordinating both plans for maximum coverage. *Read Your Rights to Health Coverage Portability (see back panel).*

6 Changing jobs and other life events can affect your health benefits. Under the Consolidated Omnibus Budget Reconciliation Act—better known as COBRA—you, your covered spouse, and dependent children may be eligible to purchase extended health coverage under your employer's plan if you lose your job, change employers, get divorced, or upon occurrence of certain other events. Coverage can range from 18 to 36 months depending on your situation. COBRA applies to most employers with 20 or more workers and requires your plan to notify you of your rights. Most plans require eligible individuals to make their COBRA election within 60 days of the plan's notice. *Be sure to follow up with your plan sponsor if you don't receive notice and make sure you respond within the allotted time. Get the facts by getting a copy of An Employee's Guide to Health Benefits Under COBRA (see back panel).*

7 HIPAA can also help if you are changing jobs, particularly if you have a medical condition. HIPAA generally limits pre-existing condition exclusions to a maximum of 12 months (18 months for late enrollees). HIPAA also requires this maximum period to be reduced by the length of time you had prior "creditable coverage." You should receive a certificate documenting your prior creditable coverage from your old plan when coverage ends. *To find out more,*

read Your Rights to Health Coverage Portability (see back panel).

8 Plan for retirement. Before you retire, find out what health benefits, if any, extend to you and your spouse during your retirement years. Consult with your employer's human resources office, your union, the plan administrator, and check your SPD. Make sure there is no conflicting information among these sources about the benefits you will receive or the circumstances under which they can change or be eliminated. *With this information in hand, you can make other important choices, like finding out if you are eligible for Medicare and Medigap insurance coverage and the new Medicare prescription drug program.*

9 Know how to file an appeal if your health benefits claim is denied. Understand how your plan handles grievances and where to make appeals of the plan's decisions. Keep records and copies of correspondence. *Check your health benefits package and your SPD to determine who is responsible for handling problems with benefit claims. Contact EBSA for customer service assistance if you are unable to obtain a response to your complaint. (See back panel for information on how to contact us.)*

10 You can take steps to improve the quality of the health care and the health benefits you receive. Look for and use things like Quality Reports and Accreditation Reports whenever you can. Quality reports may contain consumer ratings—how satisfied consumers are with the doctors in their plan, for instance—and clinical performance measures—how well a health care organization prevents and treats illness. Accreditation reports provide information on how accredited organizations meet national standards, and often include clinical performance measures. *Look for these quality measures whenever possible. Consult Your Guide to Choosing Quality Health Care at www.ahrq.gov/consumer/qntool.htm.*

GW HEATH Resource Center

The Disclosure Dilemma For Advocates

By Laverne A. Buchanan, Ed.D.



Should you? Shouldn't you? When? To whom? Such questions frequently arise for parents, counselors, and teachers whenever the topic of disclosure of a disability arises. Many disabilities, such as certain learning, cognitive, and perceptual disabilities, are not readily apparent. Students and employees with hidden disabilities may be understandably reluctant to disclose information about the presence and nature of a disability for fear of discrimination and negative perceptions.

Many factors can influence the ultimate decision of whether or not disclosure is the best course of action in a given circumstance. Young adults engaged in the transition to postsecondary education and employment will benefit from counsel and guidance about how to make sound judgments regarding disclosure.

Counselors, advocates, and family members should reinforce any advice regarding disclosure with instruction about effective self-determination and self-advocacy, concepts with which students in transition should be familiar. Ultimately, students and employees with disabilities who can articulate their particular needs and objectives, and who have been coached on the selective sharing of personal information, enjoy greater control over their circumstances.

Questions About Disclosure

There are many points of view about whether or not it is necessary or beneficial to disclose information about a disability, and, as noted above, many valid concerns about when, how and to whom such information should be shared. The following questions will guide students and advocates to a clear understanding about this difficult issue.

Why to Disclose?

There may be any number of reasons that an individual is confronted with a decision about disclosure:

- An accommodation is needed
- Legal reasons
- Background check is pending
- Safety or other health related reasons

When the disclosure question arises, individuals with disabilities need to address their own feelings about sharing personal information related to the disability.

When to Disclose?

The choice of when to disclose depends on the type of information being shared. Generally, disclosure occurs:

- When the individual is assured of the confidentiality of the information being shared, and never before.
- During initial contact, such as a job application.
- When an interview is scheduled.
- During an interview.
- Following a job interview or acceptance into a program.
- Any time after employment or program has started.
- Never.

Students and employees may choose never to disclose if no accommodations are needed and their disabilities create no safety issues for themselves or classmates and coworkers.

What to Disclose?

Once the decision to disclose is made, one must still consider how much is too little, too much, or just enough personal information to share in light of the desired objective. Always be focused on the *purpose* of disclosing. When providing information about a disability, it is best to:

- Be honest, straight forward, factual, and positive.
- Relate disclosure comments to the immediate situation.
- Know your accommodations needs, and be prepared to offer suggestions regarding such things as costs, suppliers of needed devices, and knowledge of maintaining a piece of assistive equipment.
- Be prepared to provide appropriate documentation of the disability.

Who to Tell?

Not every person that students or employees with disabilities encounter throughout the day needs to know about the disability. Generally, those who might need to know about the disability are:

- Anyone directly involved in providing accommodations.
- Anyone who is positioned to support the request for accommodations.
- Anyone who is responsible for evaluating the student or employee's performance.
- Anyone responsible for the health and safety of other students or employees.

How to Disclose?

How, or in what form, information about a disability is best shared depends, in part, on when the individual chooses to disclose, and how much information they intend to share. Generally, the disclosure may be:

- Verbal: e.g., a perspective job applicant requests an accommodation in order to complete the application and interview process.

- Written: e.g., in response to an acceptance letter, a student notifies a college about the disability and need for accommodations.
- Third party: e.g., an advocate, such as a job coach, requests assistance on behalf of an employee with a disability.

Where to Disclose?

Students, employees, and advocate should take great care in choosing a setting in which to disclose. Without question, any information of a personal nature should be provided:

- In a private setting.
- In a place where only the intended recipient of the information will be informed.

Instructive advocacy leads to effective self-advocacy. Openly discuss prospective students' and employees' questions and concerns about disclosure. Actively engaging their input in the process will prepare them to handle similar future challenges independently. Taking the time to sort through these questions will also convey a sense of empowerment, and an understanding that, like any other students or employees, they too are entitled to privacy and dignity.

Disclosure Do's and Don'ts for Advocates

The following is a list of Disclosure Do's and Don'ts for Advocates:

DO:

- Link discussion of disclosure to self-determination and self-advocacy.
- Engage the youth/young adult in a discussion regarding thoughts and feelings on disclosing personal information.
- Determine the reason for needing to disclose.

- Weigh benefits and risks of disclosure or not disclosing.
- Plan and, if necessary, practice with the youth how to disclose personal information.
- Determine who needs to have this personal information and why; limit information sharing to essential persons.
- Assure the youth that both written and verbal information will be maintained in a confidential manner.
- Get the permission of the youth and parents/guardians to share personal information.
- Relate disclosure comments to current situation.
- Be aware of accommodation needs; be prepared to provide appropriate documentation.
- Discuss private information in a private setting.

DON'T:

- Share personal information about the youth/young adult without his/her consent and involvement, or the consent of parents/guardians.
- Discuss personal information regarding the youth/young adults with persons who are not involved in their service delivery.
- Ask personal or specific questions in a group or public settings.
- Leave written information in an area that may be read by others not involved in the delivery of services to the youth.

- Use confidential information for any reason(s) other than the purpose for which it was collected, disclosed and indicated to youth and parents/guardians.

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Health and Ready to Work (HRTW) National Resource Center Health Insurance Policy/Advocacy Centers

Policy/Advocacy Centers

AIMMM - Advancing Independence: Modernizing Medicare and Medicaid

www.aimmm.org/

AIMMM's full name and mission are one and the same—Advancing Independence: Modernizing Medicare and Medicaid. AIMMM is a policy forum that identifies and advances responsible reforms in Medicare and Medicaid needed to increase the health, independence, and self-sufficiency of persons with disabilities. It brings people with disabilities, families, Federal and State officials, the media and others around a common table to identify effective ways to advance needed change in policy and real people's lives. Toward this end, AIMMM is committed to working to identify, better understand and highlight effective reforms and best practices. We created AIMMM after serving as advisors to the U.S. Secretary for Health and Human Services and the Health Care Financing Administrator. We did this because we are convinced by our disabilities and our experiences at HHS that you cannot advance the independence of people with disabilities without working to significantly modernize both programs.

CENTER FOR MEDICARE ADVOCACY

www.medicareadvocacy.org/default.htm

The Center for Medicare Advocacy, Inc., founded in 1986, is a private, non-profit organization which provides education, advocacy, and legal assistance to help elders and people with disabilities obtain necessary healthcare. We focus on the needs of Medicare beneficiaries, people with chronic conditions, and those in need of long-term care. The organization is involved in writing, analytical research, and litigation activities of importance to Medicare beneficiaries nationwide.

The Center is staffed by attorneys, paralegals, nurses, information management experts, and technical assistants. Our national office is in Connecticut, the Data Unit is in Maine, and the Healthcare Rights Project is in Washington, DC.

The Center represents thousands of individuals in appeals of Medicare denials. The work of the Center also includes responding to over 6,000 calls annually on a toll free telephone line in Connecticut, producing educational and self-help materials, and pursuing Medicare coverage for dually eligible beneficiaries (individuals who are eligible for both Medicare and Medicaid).

CENTER FOR MEDICARE ADVOCACY

Finding Reliable Health-Care Information on the Internet

www.medicareed.org/Resources.cfm?RT=CMEPub&Detail=83

The number of Web sites offering health and health-care information has grown dramatically over the past several years. However, it can be difficult to tell whether or not the information that you find is reliable and accurate. In this brief we describe the nature of this issue and offer some practical tips for judging reliability when searching for information on the Internet.

NHLEP – NATIONAL HEALTH LAW PROGRAM

Health Care "Coach"

www.healthcarecoach.org

Getting the health care you and your family needs isn't always easy in a system that's constantly changing. HealthCareCoach.com is packed with facts and do-it-yourself tips on everything from health insurance to patient care - to help you help yourself. For over three decades, our independent, non-profit group of health law specialists has given consumers the information they need to get the best out of the system. The site has three sections: 1) Your Insurance-provides tips on getting and understanding insurance and protecting your coverage; 2) Your Health-explains how to get your health plan to cover your health condition, how to find a doctor or hospital, and how to understand medical terminology; and 3) Your Action Center-explains your rights as a health care consumer and how to communicate your concerns to health policymakers.

