# THE INDEPENDENT



the hardest battle is to be nobody-but-yourself in a world that is trying to make you like everybody else e.e. cummings

December 2007

#### A Winter Eden by Robert Frost

A winter garden in an alder swamp,
Where conies now come out to sun and romp,
As near a paradise as it can be
And not melt snow or start a dormant tree.

It lifts existence on a plane of snow
One level higher than the earth below,
One level nearer heaven overhead,
And last year's berries shining scarlet red.

It lifts a gaunt luxuriating beast
Where he can stretch and hold his highest feat
On some wild apple tree's young tender bark,
What well may prove the year's high girdle mark.
So near to paradise all pairing ends
Here loveless birds now flock as winter friends

So near to paradise all pairing ends:
Here loveless birds now flock as winter friends,
Content with bud-inspecting. They presume
To say which buds are leaf and which are bloom.

A feather-hammer gives a double knock.
This Eden day is done at two o'clock.
An hour of winter day might seem too short
To make it worth life's while to wake and sport.

Merry Christmas and a Happy New Year

**From Staff** 

Tasheena M from Jamestown High School.

**Chris** 

Dick

Linda

Marie

Helen

Don

#### How to Evaluate Health Information on the Internet

Millions of consumers are using the Internet to get health information. And thousands of Web sites are offering health information. Some of those sites are reliable and up-to-date; some are not. How can you tell the good from the bad?

First, it's important to carefully consider the source of information and then to discuss the information you find with your health care professional. These questions and answers can help you determine whether the health information you find on the Internet or receive by e-mail from a Web site is likely to be reliable.

Qs & As: Evaluating Internet Health Information

#### 1. Who runs the Web site?

Any good health Web site should make it easy to learn who is responsible for the site and its information. On the U.S. Food and Drug Administration's (FDA) Web site, for example, the FDA is clearly noted on every major page, along with a link to the site's home (main) page, www.fda.gov.

Information about who runs the site can often be found in an "About Us" or "About This Web Site" section, and there's usually a link to that section on the site's home page.

2. What is the purpose of the Web site?

Is the purpose of the site to inform? Is it to sell a product? Is it to raise money? If you can tell who runs and pays for the site, this will help you evaluate its purpose. Be cautious about sites trying to sell a product or service.

Quackery abounds on the Web. Look for these warning signs and remember the adage "If it sounds too good to be true, it probably is."

- Does the site promise quick, dramatic, miraculous results? Is this the only site making these claims?
- Beware of claims that one remedy will cure a variety of illnesses, that it is a "breakthrough," or that it relies on a "secret ingredient."
- Use caution if the site uses a sensational writing style (lots of exclamation points, for example.)
- A health Web site for consumers should use simple language, not technical jargon. Get a second opinion. Check more than one site.
  - 3. What is the original source of the information on the Web site?

Always pay close attention to where the information on the site comes from. Many health and medical Web sites post information collected from other Web sites or sources. If the person or organization in charge of the site did not write the material, the original source should be clearly identified. Be careful of sites that don't say where the information comes from.

Good sources of health information include

 Sites that end in ".gov," sponsored by the federal government, like the U.S. Department of Health and Human Services (www.hhs.gov), the FDA (www.fda.gov), the National Institutes of Health (www.nih.gov), the Centers for Disease Control and Prevention (www.cdc.gov), and the National Library of Medicine (www.nlm.nih.gov);

- .edu sites, which are run by universities or medical schools, such as Johns Hopkins University School of Medicine and the University of California at Berkeley Hospital, health system, and other health care facility sites, like the Mayo Clinic and Cleveland Clinic;
- .org sites maintained by not-for-profit groups whose focus is research and teaching the public about specific diseases or conditions, such as the American Diabetes Association, the American Cancer Society, and the American Heart Association;
- Medical and scientific journals, such as The New England Journal of Medicine and the Journal of the American Medical Association, although these aren't written for consumers and could be hard to understand.
- Sites whose addresses end in .com are usually commercial sites and are often selling products.

# 4. How is the information on the Web site documented?

In addition to identifying the original source of the material, the site should identify the evidence on which the material is based. Medical facts and figures should have references (such as citations of articles in medical journals). Also, opinions or advice should be clearly set apart from information that is "evidence-based" (that is, based on research results).

# 5. How is information reviewed before it is posted on the Web site?

Health-related Web sites should give information about the medical credentials of the people who prepare or review the material on the Web site.

# 6. How current is the information on the Web site?

Web sites should be reviewed and updated on a regular basis. It is particularly important that medical information be current, and that the most recent update or review date be clearly posted. These dates are usually found at the bottom of the page. Even if the information has not changed, it is helpful to know that the site owners have reviewed it recently to ensure that the information is still valid. Click on a few links on the site. If there are a lot of broken links, the site may not be kept upto-date.

# 7. How does the Web site choose links to other sites?

Reliable Web sites usually have a policy about how they establish links to other sites. Some medical Web sites take a conservative approach and do not link to any other sites; some link to any site that asks or pays for a link; others link only to sites that have met certain criteria. Look for the Web site's linking policy, often found in a section titled "About This Web Site."

# 8. What information about its visitors does the Web site collect, and why?

Web sites routinely track the path visitors take through their sites to determine what pages are being used. However, many health-related Web sites ask the visitor to "subscribe" or "become a member." In some cases, this may be done so they can collect a fee or select relevant information for the visitor. In all cases, the subscription or membership will allow the Web site owners to collect personal information about their visitors.

Many commercial sites sell "aggregate" data about their visitors to other companies—what percent are women with breast cancer, for example. In some cases, they may collect and reuse information that is personally identifiable, such as a visitor's ZIP code, gender, and birth date.

Any Web site asking users for personal information should explain exactly what the site will and will not do with the information. The FDA Web site, for example, spells this out in its Privacy Statement. Be sure to read and understand any privacy policy or similar language on the site, and don't sign up for anything you don't fully understand.

# 9. How does the Web site manage interactions with visitors?

There should always be a way for visitors to contact the Web site owners with problems, feedback, and questions. The FDA's Web site provides contact information on its Contact Us page.

If the site hosts a chat room or other online discussion areas, it should tell its visitors about the terms of using the service. Is the service moderated? If so, by whom, and why? It is always a good idea to spend time reading the discussion without joining in, to feel comfortable with the environment, before becoming a participant.

# 10. Can the accuracy of information received in an e-mail be verified?

Carefully evaluate e-mail messages. Consider the origin of the message and its purpose. Some companies or organizations use e-mail to advertise products or attract people to their Web sites. The accuracy of health information may be influenced by the desire to promote a product or service.

# 11. Is the information that's discussed in chat rooms accurate?

the reliability of health Assessing information that you come across in Web discussion groups or chat rooms is at least as important as it is for Web sites. Although these groups can sometimes provide good information about specific diseases or disorders, they can also perpetuate misinformation. Most Internet service providers don't verify what is discussed in these groups, and you have no way of knowing the qualifications or credentials of the other people online. Sometimes people use these groups to promote products without letting on that they have a financial stake in the business. It's best to discuss

anything you learn from these groups with your health care professional.

Here's how the federal government protects consumers from false or misleading claims posted on the Internet:

#### **A Quick Checklist**

You can use the following checklist to help make sure that the health information you are reading online can be trusted.

- Can you easily see who sponsors the Web site?
- Is the sponsor a government agency, a medical school, or a reliable health-related organization, or is it related to one of these?
- Is there contact information?
- Can you tell when the information was written?
- Is your privacy protected?
- Does the Web site make claims that seem too good to be true? Are quick, miraculous cures promised?

Reprinted from the disability lifestyle magazine New Mobility 888/850-0344, www.newmobility.com."

Patrons can select tapes and receive them through the mail. The tapes can be kept for up to 60 days. They are then mailed back to R4R "Free Matter for the Blind "using the provided return label.

Recovery (R4R) was founded as a non-

profit music Library in 1958. R4R was

established to promote the use of music with special populations to enhance their

quality of life. The company has over 1200

titles with 26 categories of music, short

stories and sound effects.

Individual memberships are only \$10.00 per year. Service will not be denied to those who cannot afford it. Call R4R at 1-800-798-1192 to receive an information pack containing a large print catalog, membership information and a large print order form or go to http://www.r4r.org/aboutus.htm.

# RECORDINGS FOR RECOVERY

Recordings for Recovery (R4R) is a music library for everyone. Recordings for



#### **EDITORAL**

Election Night I was half listening to the very early election returns on Cable 8 News. Because I was only half listening to very early returns, I do not have exact figures. But what I heard was very disturbing.

According to first reports, approximately 7,000 people voted in the Jamestown mayoral race. According to the U.S. Census web site (http://factfinder.census.gov), Jamestown's population in 2000 was 31,730; 28,616 of whom were over 18 and eligible to vote.

If only about 7,000 city residents voted, that means that only about 1 in 4 eligible people voted. (Site does not give any information on citizenship; it listed only 700 people as being foreign born.)

You'll notice that I don't provide any statistics on disability. For one thing, the way the Census bureau uses the "disability" category is very broad; I assume it can refer to anyone from those who are able to work despite their disability to those who are unable to leave their place of residence for any reason.

To step down off my high horse a bit, I'm sure absentee ballots will improve the percentage of voters slightly. But even given absentee ballots, only slightly more than 1 in 4 people over 18 voted.

I confess that many times local issues do not seem as pressing as national ones. The debate on sharing the "bed tax" revenue seems to go on forever. The pros and cons of the proposed Jamestown power plant are hopelessly confusing. But these are issues that actually affect your lives more than national issues.

Readers, you should not take all the heat for this low turnout. But ask yourself, **Did vou vote?** 

#### **FOR SALE**

HOYER LIFT WITH TWO SLIDES \$200

COMPLETE HOSPITAL BED WITH ALARM AND BEDDING \$250

ELECTRIC WHEELCHAIR- 5 YEARS OLD \$500

FOR INFORMATION CALL JUNE WHIPPLE AT 410- 6604

# American Association of People with Disabilities 2008 Election Guide

The American Association of People with Disabilities (AAPD) has established a webpage on disability issues and the 2008 Presidential Election. A collaboration of AAPD, the National Council on Independent Living (NCIL), Self-Advocates Becoming Empowered (SABE), and ADAPT developed a set of questions which were posed to the currently announced presidential candidates. Responses have been coming in over the last few weeks. Additional responses will be posted as they are received. These responses and other information can be found on the AAPD 2008 Election Home Page at http://www.aapddc.org/News/election/peac2008.php

FROM NYS E-BULLETIN NOVEMBER 2007

#### Smoking Rates Highest Among People with Disabilities

Health Disparities Persist Among People
with Disabilities
From the Dept. of Health and Human
Services

Smoking prevalence among people with disabilities is nearly 50 percent higher than among people without disabilities (29.9)

percent vs. 19.8 percent), according to a new study from the Centers for Disease Control and Prevention (CDC) "Preventing Chronic Disease".

The study found that about 70 percent of people with disabilities who smoke and had visited a doctor in the last year had been advised to quit smoking. However, more than 40 percent of those advised to quit reported not being told about the types of tobacco-cessation treatment available.

"About 50 million Americans are living with a disability and most Americans will experience a disability some time during the course of their lives," said Dr. Edwin Trevathan, director of CDC's National Center on Birth Defects and Developmental Disabilities. "The release of these findings during Disability Awareness Month reminds us that disparities persist in the health and health care of people with disabilities."

People who stop smoking greatly reduce their risk of dying prematurely. Benefits are greater for people who stop at earlier ages, but cessation is beneficial at all ages. Smoking cessation lowers the risk for lung and other types of cancer. The risk for developing cancer declines with the number of years of smoking cessation.

Quitting smoking is the most important step smokers can take to improve their overall health and reduce their risk for disease. Approximately 10 percent of smokers have a smoking-related chronic disease, primarily heart disease or emphysema. Smokers who quit will, on average, live longer and have fewer years living with disability.

Disparities in smoking prevalence, in addition to barriers to the use of preventive

services (such as traveling to a doctor's appointment) put people with disabilities at risk for declining health. Researchers are unsure why the smoking prevalence is higher in people with disabilities, but it is an area for further examination. However, research confirms that people with disabilities are less likely than people without disabilities to receive preventive health care and therefore are more subject to illness and disease. As per the 2005 Surgeon General's Call to Improve the Health and Wellness of Persons with Disabilities, the resulting higher health care expenditure costs and productivity losses for people with disabilities, which exceeds \$300 billion, can be understood as a result of too little attention to the other health needs of these individuals by health providers.

This data was collected from the 2004 Behavioral Risk Factor Surveillance System (BRFSS) from the 50 states, the District of Columbia and the two U.S. territories for which data were available—Puerto Rico and the U.S. Virgin Islands. The BRFSS is an ongoing, state-based, random-digit-dialed telephone survey of the civilian, non-institutionalized U.S. population aged 18 years or older. It is designed to collect information on demographics, health status, behavioral health risk factors and preventive health behaviors.

The 2004 BRFSS questionnaire included two questions on disability screening: "Are you limited in any way in any activities because of physical, mental, or emotional problems?" and "Do you now have any health problem that requires you to use special equipment, such as a cane, a wheelchair, a special bed, or a special telephone?" Respondents were defined as

having a disability if they answered yes to either of these questions.

People with and without disabilities who smoke can call 1-800-QUIT-NOW (1-800-784-8669) (TTY 1-800-332-8615) or visit <a href="https://www.smokefree.gov">www.smokefree.gov</a> for quitting assistance. The toll-free number is a single access point to the National Network of Tobacco Cessation Quit lines. Callers are automatically routed to their state's quit line services.

FROM NYS E-BULLETIN NOVEMBER 2007

# IMPORTANT MEDICARE PART D INFORMATION

Just because you were happy with your Medicaid Part D health plan last year, don't become complacent. Many plans are changing. Eight of the most popular plans have undergone significant revisions, so you need to look at the current benefits package.

Between now and January 1, 2008 is the **only** time you can switch plans. Take the time to gather all of the information you'll need to make a decision about your health and prescription coverage.

#### Look at

- A list of medications you take
- A list of providers you want to use, like your doctor or pharmacy

- Any notice from your plan (called the Annual Notice of Change), Social Security or Medicare about changes to your costs and coverage for next year
- Information about other plans in your area for next year

The next step is to visit www.medicare.gov on the web or talk to an advisor and compare all of your options and to search for plans in your area. Think about:

- Cost- Will your premium and other costs change next year? Are there plans that will cost you less?
- Coverage- Are your providers, like your doctor, hospital or pharmacy part of your plan for next year? Will the prescription drugs you take be covered by your plan?
- Customer Service-Are you satisfied with the service and quality you get from your plan, such as your Medicare Advantage Plan or Medicare Prescription Drug Plan?

Decide which plan is right for you for next year. If you want to switch plans, call the plan you want to join. Medicare can also help you enroll- online, in person, at an event in your community, or on the telephone.

If you need further assistance, call Linda at 661-3010. Remember any changes have to be made by January 1, 2008.

PLEASE CONTINUE TO SAVE LABELS FROM CAMPBELLS PRODUCTS FOR

SOUTHWESTERN
INDEPENDENT LIVING
CENTER.

ITS AN EASY WAY TO SUPPORT A GOOD CAUSE.



#### PEDIATRIC HEARING AID LOANER BANK ESTABLISHED BY OTICON

Oticon Pediatrics has unveiled a program designed to assist hearing care professionals in providing care for infants and toddlers newly identified with hearing loss.

The Loaner Bank provides hearing instruments for a 3-month period to children under the age of 3 while arrangements for third-party reimbursement are secured or while cochlear implant evaluation is underway. A range of Oticon hearing instruments will be offered. An EarGear hearing aid retention device will be provided with each loaner hearing instrument order.

To utilize the Loaner Bank, hearing care professionals must have an Oticon account and complete a one-time application to participate in the program. Upon acceptance, practitioners must verify they have completed training on Oticon fitting software and the available loaner hearing instruments. Hearing care professionals must also submit a request form for each child requesting hearing aids. There is no fee to participate in the program.

For more information about the Oticon Pediatrics Loaner Bank Program, contact Maureen Doty-Tomasula at <a href="mdd@oticonusa.com">mdd@oticonusa.com</a> or phone 888-OTI-PED1 (1-888-684-7331).

FROM NYS E- BULLETIN NOVEMBER 2007

# Information Fact Sheet on Service Animals in Places of Business

A fact sheet answering commonly asked questions about the use of service animals by people with disabilities in places of business has recently been updated. It can be accessed at www.usdoj.gov.

All fact sheets concerning employment laws and regulations can be seen by following the link: service.govdelivery.com.

Information from NYS E-ulletin October 2007





# TRANSITION

#### **NEWS**

# Perceptions and Expectations of Youth with Disabilities

A Special Topic Report of Findings from the National Longitudinal Transition Study-2, completed August 2007 completed by the Institute of Education Services, U.S. Dept. of Education can be found on the internet at http://ies.ed.gov/ncser/pdf/20073006.pdf

The National Center for Special Education Research supports a comprehensive research program to promote the highest quality and rigor on special education and related services and to address the full range of issues facing children with disabilities, parents of children with disabilities, school personnel and others.

#### Some of the topics covered include:

- Understanding the Perceptions of Youth with Disabilities
- Youth with Disabilities Views of Themselves and their Lives
- Self-Evaluations of the Strengths and Competencies of Youth with Disabilities
- Youth with Disabilities Views of Secondary School

- 5. Views of Personal Relationships
- 6. Youth's Expectations for the Future
- 7. A National Picture of the Self-Reported Perceptions and Expectations of Youth with Disabilities

# In Service Learning Manual

In Service Learning is an approach to teaching and learning that combines real and needed community service with prescribed academic learning goals. The Magellan Foundation in collaboration with the New York State Education Department Learn and Serve America Program, with funding from Developmental Disabilities Planning Council and the Corporation for National and Community Service, worked with numerous school districts in recent years to assist schools with including children with disabilities in service learning programs. As a result of this inclusive service learning project a manual was developed to provide instructions and technical assistance to other districts who are interested in students with and without disabilities working sideby-side on service learning activities. If you are interested in obtaining a CD copy of the manual, please contact Fran Hollon at the NYS Education Department

fhollon@mail.nysed.gov or Kerry Wiley at kwiley@ddpc.state.ny.us or call DDPC at 1-800-395-3372. THIS DOCUMENT CAN BE DOWNLOADED FROM http://www.ebulletin.us/pages/publications.phpOctober 2007

# TRANSPORTATION FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

Through a grant from the Western New Services Developmental Southwestern Independent Living Center provides FREE evening and weekend wheelchair accessible transportation to Chautauqua County residents who are living with family members. This service is not exclusively for people living with parents. Riders can live with their parents, spouse or their own children. Riders can use this transportation service throughout the county for recreational purposes. Riders must provide documented proof of disability.

For more information, call Helen at 661-3010.

THIS NEWSLETTER CAN BE MADE
AVAILABLE IN ALTERNATIVE
FORMATS- LARGE PRINT, BRAILLE,
TAPE AND E-MAIL. FOR MORE
INFORMATION, CALL CHRIS AT
661-3013(V/TTY) OR E-MAIL ME
AT chris@info-jamestown-ny.org.

# Successfully Supporting All Children in Early Childhood Education Programs

The New York State Developmental Disabilities Planning Council is pleased to announce the availability of a new publication, Successfully Supporting All Children in Early Childhood Education Programs"

In 2006, NYS DDPC sought articles from early care and education programs from across the State to document successful experiences related to:

- implementing models that built partnerships and collaboration between programs which supported the inclusion of children with and without disabilities in activities,
- training and technical assistance that support inclusive child care practices, and
- successful strategies for addressing policy or practice barriers.

This publication details promising strategies and approaches used by child care providers to include children with disabilities in early care and education programs.

Electronic copies of the publication can be obtained by visiting www.ddpc.state.ny.us or hard copies can be requested by contacting Kerry Wiley, at DDPC, at 1-800-395-3372 or via email at kwiley@ddpc.state.ny.us.

### GEOGRAPHY -FIND A WORD- FIND THE COUNTRIES HIDDEN IN THIS PUZZLE

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Sweden (Europe)
Togo (Africa)
Trinidad and Tobago (West Indies)
United States (N. America

Albania (Europe) Algeria (Africa) Andorra (Europe) Austria (Europe) Bahrain(Arabian Peninsula) Bangladesh (Asia) Belize(Central America) Benin (Africa) Botswana (Africa) Brazil (S. America) Chile (S. America) Congo (Africa) Cuba (West Indies) Egypt (Africa) Gabon (Africa) Gambia (Africa) Guatemala(S. America) Greece (Europe) Haiti (West Indies) Hungry (Europe) Iran (Middle East) Japan (Asia) Jordon (Middle East Kygyzstan (Central Asia) Laos (Asia) Lesotho (Africa) Macedonia (Europe) Malta (Mediterranean) Namibia (Africa) Nauru (Pacific Island) Nepal (Asia) Norway (Europe) Oman (Middle East) Panama (Ct. America) Peru (S. America) Qatar (Middle East) Russia Asia) Senegal (Africa) Spain (Europe)

Sudan (Africa)

# SOUTHWESTERN INDEPENDENT LIVING CENTER WILL BE CLOSED DECEMBER 24, 25 AND JANUARY 1.

information below, check the a Living Center, Inc., 843 North N 3010); or 661-3012 (TDD). E-ma ny.org	nore information about the services we provide, please fill in the appropriate box/ boxes and return it to Southwestern Independent Main Street, Jamestown, NY 14701. Or you may call us at (716-661-ail- info@ilc-jamestown.ny.org; web site- http://www.ilc-jamestown-
Name:Address:	
	Phone
Peer Support	Individual and Group sessions.
Advocacy	Assistance with legal and economic rights.
Housing  Transportation  Information and	Assistance in locating adequate, affordable, and accessible housing Wheelchair Accessible van available for medical and social appointments Information about other area services and
Referral  TDD Relay Calls	organizations. For hearing impaired individuals with $\underline{T}$ elecommunication $\underline{D}$ evices for the $\underline{D}$ eaf
Public Education	Regarding issues pertaining to people with disabilities.
Newsletter	A bi-monthly publication of SILC.
SILC Membership	A one year membership is \$5
WIPA	Work Incentives Planning and Assistance