



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

WINTER 2006, VOL.19 NO. 4

**TRANSITION NEWS
BEGINS ON PAGE 9**

SOME THOUGHTS FOR THE NEW YEAR AND BEYOND; HOPEFUL AND NOT SO HOPEFUL.
WHICH ARE YOU?

**We spend January 1 walking through our lives, room by room,
drawing up a list of work to be done, cracks to be patched.
Maybe this year, to balance the list, we ought to walk through
the rooms of our lives... not looking for flaws, but for potential.
~Ellen Goodman**

**May all your troubles last as long as your New Year's
resolutions. ~Joey Adams**

HAPPY HOLIDAYS

Quotes from <http://www.quotegarden.com>



THANK YOU
WE WISH TO THANK
STEVE SMITH
FOR HIS
GENEROUS
DONATION

**Emergency Preparedness
for Children with Special
Health Care Needs**

In our rapidly changing high tech health care environment, children with very special health care needs are increasing. Kids with high tech medical gear are becoming common in the community. Children with very complex and difficult health care needs which not only include rare genetic and metabolic problems but also those with difficult to manage asthma, diabetes, sickle cell disease, malignancies, and a variety of other problems are increasing. Because of the complex and varied needs of these children, they are often lost in the cracks between the specialists and the primary care medical home. When a crisis occurs and children with special health care needs must access the emergency system, they are often left vulnerable because of a lack of access to information about their medical problems. There can be delays in treatment, unnecessary tests, and sometimes serious errors as a result of lack of access to information available to the treating emergency physician.

To facilitate prompt and appropriate emergency care for children with special health care needs, the American Academy of Pediatrics (AAP) and the American College of Emergency Physicians (ACEP) have developed an Emergency Information Form which can be used as a tool to transfer

critical information about these children. It is hoped that the form will gain acceptance and be utilized by primary caregivers and specialists so that emergency physicians may have access to vital information when emergencies occur. The form and policy guidelines on developing emergency care plans were simultaneously published in the October 1999 issues of Pediatrics and Annals of Emergency Medicine, and are accessible on the AAP and ACEP Web sites. A blank and sample copy of the Emergency Information Form can be downloaded at [http://www/aap.org/healthtopics/special_needs.cfm](http://www.aap.org/healthtopics/special_needs.cfm) and may be duplicated as needed. The blank form will also be sold in pads of 100 at a nominal cost through AAP Publications (Please call 888/227-1770).

Please review the AAP and ACEP guidelines along with the Emergency Information Form and work to make the form available to emergency care providers as necessary. MedicAlert® Foundation, a nonprofit 501c(3) organization has also agreed to serve as a repository for the data (for any child who registers with the MedicAlert® program) collected via the Emergency Information Form. Robert A. Wiebe, MD, Chairperson AAP Committee on Pediatric Emergency Medicine, August 2006

FLOATERS

By Fred Cicetti

More than 7 of out 10 people experience floaters. The lens in the front of your eye focuses light on the back of the eye. The lens is like the one in a camera, and the retina is like film. The space between the lens and the retina is filled with the "vitreous", a clear gel that helps to maintain the shape of the eye.

Floater occur when the vitreous slowly shrinks over time. As the vitreous changes, it becomes stringy, and the strands can cast shadows on the retina. These strands are floaters. They can look like specks, filaments, rings, dots, cobwebs or other shapes. Floaters are the most vivid when you are looking at the sky or a white surface such as a ceiling. They move as your eyes move and seem to dart away when you try to look at them directly.

In most cases, floaters are just annoying. When you discover them, they are very distracting. But, in time, they usually settle below the line of sight. Most people who have visible floaters gradually develop the ability to make them “disappear” by ignoring them.

When people reach middle age, the vitreous gel may pull away from the retina, causing “posterior vitreous detachment”. It is a common cause of floaters, and is more likely in people who are diabetic, nearsighted, had eye surgery, or suffered inflammation inside the eye.

These vitreous detachments are often accompanied by light flashes. These flashes can be a warning sign of a detached retina. Flashes are also caused by head trauma that makes you “see stars”. Sometimes light flashes appear to be little lightning bolts or waves. These flashes are usually caused by a blood-vessel spasm in the brain. These flashes can happen without a headache and they are called an “ophthalmic migraine”.

If your floaters are just bothersome, eye doctors will tell you just to ignore them. In rare cases, a bunch of floaters can hamper sight. Then a “vitrectomy” may be necessary. A vitrectomy is a surgical procedure that removes the vitreous gel with its floaters. A salt solution replaces the vitreous. The vitreous is mostly water, so patients who undergo the procedure don’t notice a difference.

However, this is a risky procedure, so most eye surgeons won’t recommend it unless the floaters are a major impediment.

Many new floaters can sometimes appear suddenly. When this happens, it usually is not sight-threatening and requires no treatment. However, a sudden increase in floaters can mean that a part of the retina has pulled away from its normal position at the back wall of the eye. A detached retina is a serious condition and demands emergency treatment to prevent permanent impairment or even blindness.

What should you do when you notice your first floater? Get that eye examination you’ve been putting off.

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ACCESSIBLE SHOPPING

The Better Business Bureau has put out a series of brochures Access Equals Opportunities- dealing with the Americans with Disabilities Act in retail stores, grocery stores, medical offices, restaurants and bars, and finally car sales and service. Each brochure contains a question and answer section.

RETAIL STORES

Q. Are retail stores required to have TDDs (Telecommunications Devices for the Deaf)
A. No, For making calls to or receiving calls from customers with hearing or speech impairments who used TDDs, stores can relay on the New York State relay systems. Operators employed by relay systems will relay communications between TDD-users and people using conventional telephones. Only those businesses that allow customers

to make outgoing calls on more than incidental convenience basis must provide TDDs.

Q. Are retail stores that offer parking required to provide accessible parking spaces?

A. Yes, If a retail store owns and operates a parking lot, it must provide accessible parking if it is readily achievable to do so. If the retail store is a tenant, responsibility for providing accessible parking rests with both the tenant and the landlord. These responsibilities may be allotted between the landlord and tenant in the lease or other contract.

Q. Are retail stores required to remove barriers posed by sidewalk curbs?

A. If the only parking available is on a city street and the business does not have ownership control of the side walk, then the municipality, not the store, is responsible for providing curb ramps (cuts). If the store owns or controls the sidewalk, it must provide curb cuts if readily achievable. If the retail store is a tenant, responsibility for providing curb cuts rests with both the tenant and the landlord. These responsibilities may be allotted between the landlord and tenant in the lease or other contract.

Q. Must all entrances to retail stores be accessible?

A. No, but one entrance, preferably the main entrance must be accessible. For most businesses, ramping one step or even several steps will be readily achievable.

Q. Can a retail store deny service to a person with a disability because his or her disability or behavior resulting from the disability may be disturbing to other customers?

A. No, The ADA specifically prohibits this type of discrimination against people with disabilities.

Q. How do retail stores make their merchandise accessible to customers with various disabilities?

A. Customers who use wheelchairs, crutches, or other mobility devices, customers with limited manual dexterity, and customers who are blind or who have limited vision tend to experience certain types of access problems in retail establishments. For example, people who use wheelchairs are sometimes unable to move down aisles when stock or displays are placed in them. Although widening aisles where merchandise is displayed is an ideal solution for customers who use wheelchairs, in many retail establishments it will result in a significant loss of selling space and is, therefore, in those cases not readily achievable for those stores.

Some retail stores, such as department stores, may be able to rearrange display racks and shelves in a way that does not result in a significant loss of selling space.

Placing lightweight items on higher shelves and heavier items on lower shelves and offering the use of a device for reaching high items will improve the usability of a store not only for customers with mobility impairments but also for customers with manual impairments. Otherwise, sales clerks should offer assistance in reaching items.

Moving boxes and displays that impede access to aisles or could trip a customer with a vision impairment is a simple, common sense solution to certain access problems that also makes it easier for customers who do not have disabilities.

For retail businesses housed in cramped facilities, there may be no storage alternatives for boxes placed in the aisles. If readily achievable, the store must provide service at the door to customers unable to move down the aisles.

Q. Do dressing rooms need to be accessible?

A. If it is readily achievable, stores must alter one or more dressing rooms to allow use by customers who use wheelchairs or other mobility devices. If it is not readily achievable to provide an accessible dressing room, alternative methods must be used, such as establishing a liberal return policy so customers who cannot use the dressing rooms can take merchandise home to try on.

Q. Are clothing stores required to provide assistance in dressing rooms to people with disabilities?

A. The Dept. of Justice states that dressing assistance is required in stores where individualized assistance in selecting and trying on garments is provided. In a store where such assistance is not offered generally, it is not required because it is not provided to other customers.

Q. If a store is staffed with a single cashier, is the cashier required to leave the cash register to assist a customer with a disability?

A. No. The ADA does not require a cashier to leave the register, if so doing poses a security risk.

Q. How can a retail establishment communicate with a customer who is deaf or hard of hearing or who has a speech impairment?

A. Most customers who are deaf or hard of hearing will identify themselves by writing a note or using hand gestures. When a salesperson had determined that a customer is deaf or hard of hearing, he or she can communicate by writing notes. Maintaining face-to-face contact is important for communications with a customer who reads lips.

The services of a sign language interpreter should not be necessary to accomplish most retail transactions that are short and straightforward with deaf individuals, but may be necessary to communicate effectively in an unusually complex transaction.

Stores that use public address system to announce special offers or sale days should consider providing electronic bulletin boards or print announcements near doors and check-out counters to announce these events as a way to communicate effectively with customers who are deaf or hard of hearing, if they can do so without incurring significant difficulty or expense.

It is also important for retail businesses to communicate effectively with customers who have speech impairments. Allowing sufficient time for a person with such a disability to express him or herself or read a message spelled out on a word board are examples of methods to achieve effective communication.

If you are interested in the entire brochure, please call Chris at 661-3013 for information.

**NCD Calls for
Sweeping Changes for
People with
Psychiatric Disabilities
in Emergency
Evacuation Situations**

According to NCD former chairperson Lex Frieden, "The destructive forces of Hurricanes Katrina and Rita in fall 2005 wreaked an emotional as well as a physical toll on residents of the Gulf Coast region. Millions of Americans from across the country reached out to hurricane survivors, opening their homes and their hearts. Government employees at local, state and federal levels worked long and hard to help evacuate and rescue people in the Gulf Coast. Many of these people are still in the Gulf Coast helping to rebuild communities. In the months since the hurricanes devastated the Gulf Coast, media coverage of the hurricane survivors has waned. However, for hurricane survivors with psychiatric

disabilities, the hurricanes' destruction resulted in 'trauma that didn't last 24 hours, then go away. ...It goes on and on.' Some of these challenges were unavoidable. As one government official said, 'No one ever planned for what happens when your social service infrastructure is completely wiped out.' Nonetheless, many of the problems could have been avoided with proper planning."

"As NCD predicted in its April 2005 report, *Saving Lives: Including People with Disabilities in Disaster Planning*, '[i]f planning does not embrace the value that everyone should survive, they will not.' As a result of its research, NCD found that much pre-Katrina disaster planning did not contemplate the needs of people with psychiatric disabilities, and as a result, many people died or unnecessarily suffered severely traumatic experiences," Frieden concluded.

This paper includes the following major findings and recommendations, as well as various specific recommendations for emergency management officials and policymakers at the local, state and federal levels.

Major Findings

In violation of federal policy and law, people with psychiatric disabilities were discriminated against during evacuation, rescue, and relief phases.

Mismanaged evacuations resulted in the loss, mistreatment, and inappropriate institutionalization of people with psychiatric disabilities

People with psychiatric disabilities were not included in disaster planning or relief and recovery efforts. Disaster management efforts often failed because no individual or office had responsibility, accountability, and authority for disability related issues. Disaster plans were shortsighted and relief services were terminated prematurely.

Major Recommendations

The federal National Response Plan and state and local emergency plans should require that services and shelters be accessible to people with disabilities, including people with psychiatric disabilities (who live independently or in congregate living situations such as hospitals, group homes, or assisted living), in compliance with the Americans with Disabilities Act and Section 504 of the Rehabilitation Act. State plans should be reviewed by independent disability experts familiar with those standards.

Evacuation planners should have a plan that (a) tracks the transfer of residents of group homes and psychiatric facilities; (b) maintains contact between people with psychiatric disabilities and their family members and caretakers; (c) helps facilitate the return of evacuees to their homes; (d) ensures that sites that receive evacuees are equipped to meet the needs of people with psychiatric disabilities; and (e) prevents the inappropriate institutionalization of evacuees with psychiatric disabilities.

People with psychiatric disabilities must be involved at every stage of disaster and evacuation planning and with the administration of relief and recovery efforts. Communities should develop interagency, multi-level disaster planning coalitions that include people with disabilities, similar to the coalition developed in Houston.

A single person or office must be responsible, accountable and able to make decisions related to disability issues. This person or office would be responsible for training first responders and organizing disability-specific evacuation, relief and recovery efforts. This person or office would also serve as a communication link between people with disabilities and the respective local, state or federal government.

Relief and recovery efforts should continue for at least two years from the date of the disaster, including Medicaid waivers, HUD housing waivers, and FEMA housing for

people with disabilities. Disasters often result in long-term psychiatric consequences for people, and in some cases, the traumatic impact of the disaster does not manifest itself until many months or years later. Additionally, the social service infrastructure in some locations was utterly wiped out. Emergency planners should ensure treatment continuity by planning for relief services to be available for at least two years after the disaster.

Many of these findings and recommendations align with NCD's 2005 report, "Saving Lives: Including People with Disabilities in Disaster Planning". NCD encourages policymakers, emergency planners and people with disabilities to carefully review that report. NCD stands ready to provide guidance to those who are ready to make their emergency plans and services more accessible to people with disabilities. As emergency managers and policymakers create plans that seek to ensure that all people, regardless of disability, survive catastrophes such as Hurricanes Katrina and Rita, we will incorporate the principles of inclusion and nondiscrimination into our national consciousness.

For more information, please contact Mark S. Quigley at 202-272-2004 or 202-272-2074 TTY, Director of Communications, National Council on Disability, 1331 F Street, NW Suite 850, Washington, DC 20004

Report can be found at (<http://www.ncd.gov/newsroom/publications/2006/peopleneeds.htm>),

HELPING GRANDPARENTS

The AARP of New York has issued a pamphlet entitled "Grandparents Raising Grandchildren: Know Your Rights," which is a guide designed to assist and inform people about the new laws that are helping grandparents and other kin caregivers. read Grandparents Raising Grandchildren (<http://app.quickstizzle.com/get.link?linkid=289665&subscriberid=31751633&campaignid=95169&linkurl=http://www.ebulletin.us/>

[stories/general interest/11_06_grandparents raising grandchildren.php](#))

Information appeared in E-bulletin, November 2006

FREE TAX RETURN PREPARATION FOR YOU BY VOLUNTEERS AT SILC

Puzzled by the tax law or by which credits or deductions to take? Need assistance with your tax return?

You may want to visit a volunteer site. The IRS Volunteer Income Tax Assistance (VITA) Program or the Tax Counseling for the Elderly (TCE) Program offer free tax help if you qualify. Trained community volunteers can help you with special credit, such as Earned Income Tax Credit (EITC), Child Tax Credit and Credit for the Elderly for which you may qualify. In addition to free tax return preparation assistance, most sites offer free electronic filing (e-filing). Individuals taking advantage of the e-file program will receive their returns in half the time compared to returns filed on paper—even faster if you have your refund deposited directly into your bank account.

Volunteer Income Tax Assistance Program (VITA)

The VITA Program offers free tax help to low to moderate-income (generally \$39,000 and below) people who cannot prepare their own tax

returns. Certified volunteers are sponsored by various organizations receive training to help prepare basic tax returns in communities across the country. VITA sites are generally located at community and neighborhood centers, libraries, schools, shopping malls and other convenient locations. Most locations also offer free electronic filing. To locate the nearest VITA site, call 1-800-829-1040.

TAX COUNSELING FOR THE ELDERLY (TCE)

Tax Counseling for the Elderly (TCE) provides free tax help to people age 60 or over. Trained volunteers from non-profit organizations provide free tax counseling and basic income tax preparation for senior citizens. Volunteers who provide tax counseling are often retired individuals associated with non-profit organizations that receive grants from the IRS.

As part of the IRS-sponsored TCE Program, AARP offers the Tax-Aide counseling program at more than 7,400 sites nationwide during the filing season. Trained and certified AARP Tax-Aide volunteer counselors help people of low-to-middle income with special attention to those age 60 or older.

Shortly after January 1, 2007 we will begin taking appointments. You may call Dick Johnson at 661-3014 to schedule an appointment. The basic schedule will be:

Monday 12:30 to 4:30 PM; Tuesday, Wednesday, Thursday 9:30 to 5:30; Friday 9:30 to 4:30. We can also

made special arrangements for any one who cannot make it during the regular hours.

Information appeared in E-bulletin, November 2006

TRANSPORTATION FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

Through a grant from the WNY Developmental Disabilities Services Office, SILC provides FREE evening and weekend wheelchair accessible transportation to Chautauqua County residents with developmental disabilities 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.

MERRY CHRISTMAS



TRANSITION NEWS



Top 10 Do's and Don'ts for School to Work Transition Planning

Created by the Youth Leadership Forum Alumni, a program sponsored by the Virginia Board for People with Disabilities

DO...

1. Explain the goals of transition planning – what does it mean to students?
2. Describe what students can/should expect.
3. Ask students questions to make sure they understand.
4. Ask students where they need help and how you can help. Encourage students to identify their needs.
5. Research what supports and services are available to students including other agencies.
6. Encourage students to talk about their goals and dreams; discuss ways to support them in the Transitional Plan.
7. Keep open lines of communication between all members of the IEP Team, especially students.
8. Be an advocate for students.
9. Acknowledge strengths and successes.
10. Encourage self advocacy!

DON'T...

1. Don't underestimate the relationship between transition planning and student's future success.
2. Don't forget students are young adults; treat them with respect so they can in turn respect themselves.
3. Don't forget how important it is for students to have a positive outlook about their future.
4. Don't rush...give students time to formulate their thoughts, questions and ideas.
5. Don't expect to have all the answers, LISTEN.
6. Don't say you're going to do something and then not do it.

7. Don't wait until students are 16 years old before you discuss transition, plant the seed NOW!
8. Don't assume students understand what's happening. If they understand they are able to participate.
9. Don't assume students know who you are and what your role is, EXPLAIN!
10. Don't assume anything!

Make it Matter, Make it Real. It Will Make a Difference!

July 2006

**Confidence doesn't
come out of nowhere.
It's a result of
something... hours
and days and weeks
and years of
constant work and dedication.**

~ [Roger Staubach](#) ~

NEW YEAR'S SEARCH A WORD PUZZLE

R	W	I	N	T	E	R	B	B	E	C	I	A	T
E	C	D	O	I	C	E	A	O	R	O	Y	U	W
S	H	E	I	M	O	L	B	W	E	L	T	L	E
O	A	C	S	E	M	A	Y	L	C	L	G	D	L
L	M	E	E	S	P	T	N	G	E	E	B	L	V
U	P	M	M	Q	A	I	E	A	P	G	T	A	E
T	A	B	A	U	N	V	W	M	T	E	H	N	O
I	G	E	K	A	Y	E	Y	E	I	F	G	G	C
O	N	R	E	R	R	T	A	S	O	O	I	E	L
N	E	A	R	E	S	D	E	G	N	O	N	S	O
I	C	V	S	E	I	T	R	A	P	T	D	Y	C
O	L	D	P	O	T	E	F	F	U	B	I	N	K
T	S	N	O	W	Y	A	F	O	R	A	M	E	O
M	P	A	R	A	D	E	K	B	E	L	L	B	O
N	H	A	T	S	U	F	A	M	I	L	Y	W	C
C	H	U	R	C	H	S	E	R	V	I	C	E	S
J	A	N	U	A	R	Y	W	A	T	C	H	Y	O

NEW YEAR
 WINTER
 NOISE MAKERS
 TIME SQUARE
 BABY
 TWELVE OCLOCK
 BUFFET
 RELATIVE
 WATCH
 RECEPTION

DECEMBER
 MIDNIGHT
 PARTIES
 COLLEGE FOOTBALL
 AULD LANG SYNE
 HATS
 ICE
 SPORT
 OLD
 BELL

JANUARY
 CHAMPAGNE
 RESOLUTION
 BOWL GAMES
 PARADE
 SNOW
 FAMILY
 CHURCH SERVICES
 COMPANY
 COOK

