



disAbilities Celebration Connection

FALL 2012

A Laundry List of Random Thoughts

during the years when *Celebrating Special Children* (CSC) was a hard-copy publication, I frequently got requests to publish information about this or that “for-profit” organization, school, or service provider. My response was always the same; I said that if I accepted information from every group that wanted to publicize their product or service, CSC would be the size of a phone book! I would go on to inform them that they could support CSC by placing an advertisement or becoming a sponsor; this would help us pay the enormous cost associated with creating and distributing a hard copy resource guide and provide a justification for printing their information. Many folks said no but many said yes; we are forever grateful for the support their funds provided.

But, for better or worse, those hard copy days are gone – and with them, the need to limit our information to what we could afford to print. Now that we are only online, we have as much space as we need. I continue to receive requests from “for-profit” businesses. My response now is to invite them to send me their information and if it seems to me to be appropriate to our audience, I include the information under the **Community Resource Tab**.

If this seems a little subjective, well . . . I agree, it is. I take my responsibility to our audience very seriously and I will never knowingly publish information that is faulty or takes advantage of the possible desperation or inexperience of our readers. With that caveat, I hereby invite you to send me your info – if it fits in with our reason for being, I’ll publish it. Of course you can still make a donation! The

funds will be used to support our mission - “to provide the necessary information to ensure that individuals with disabilities realize their fullest potential of development, independence and quality of life.”

Next on my list of random musings is the admission of my fear of social media. It seems that many of the Facebook pages I visit are filled with the flotsam and jetsam of “stuff;” and I did not want a CSC page to be similarly inundated. I know. I’m a dinosaur.

However, I have been recently convinced that Facebook and other social media can be used very effectively to keep our community informed in a timely manner about the many important issues and events that affect us.

And so, I am committing myself to learning how to set up a page, how to “share” with you and have you “share” with us. We’ll “Like” you and you’ll “Like” us.

Finally, I want to remark on the very eclectic mix of information presented in this newsletter – from voting information to Halloween safety, to a Department of Justice press release. In fact, it was while putting this issue together that my plan to become more savvy in the social-media realm was reinforced.

Keep checking the website to see my progress; by January I hope to have made a good beginning.

Laura Nelson, Editor

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ACCESSIBILITY: Exercising Your Right to Vote

Editor's note:

My sincere thanks to the Virginia Board for People with Disabilities (www.vaboard.org), which has the information below, with associated links, posted to its website.

VOTER REGISTRATION GUIDELINES

- ✓ Register in-person at your local registrar's office or register at home and mail your completed Voter Registration Application to your local registrar's office.
- ✓ New registrants must show an acceptable form of ID when registering to vote.
- ✓ For more information on registration, please visit the State Board of Elections website:
www.sbe.virginia.gov



Contact Information



Virginia State Board of Elections
804.864.8901 • www.sbe.virginia.gov

*Publications are available in
alternate formats upon request.*



*If you would like to apply to serve as an
Officer of Election on Election Day, please
visit: www.sbe.virginia.gov/officers*

Virginia Board for People with Disabilities
804.786.0016 • www.vaboard.org

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Annual Application Process

- Request an Annual Application from your local registrar.
- If you are a first-time applicant, you must have the form signed by your physician.
- Return the completed form to your local registrar's office.
- After the registrar processes your application, you will receive a ballot for every election for which you are eligible during the calendar year.
- In December, your local registrar will mail you another Annual Application for the following calendar year.



Application to Vote Absentee

By Mail

- Request an Absentee Application from your local registrar.
- Return the completed form to your local registrar's office.
- After the registrar processes your application, you will receive your ballot in the mail.
- Fill out your ballot and return to your local registrar by 7pm on Election Day.

In-Person

- Within 45 days prior to the election in which you wish to vote, visit your local registrar's office to vote absentee in-person.
- At the registrar's office, fill out an Absentee Application. You must show an acceptable form of ID.
- After completing the application, you will be allowed to vote absentee in-person using a voting machine in the registrar's office. Accessible equipment is available upon request



Voting on Election Day

- Present an acceptable form of ID to the poll worker.
- Cast your ballot using one of the voting machines located in the polling place. Accessible equipment is available upon request.

- If needed, Assistance Forms are available for your use.



Curbside Voting

- Notify poll workers of your arrival at the polling place by activating the call bell located outside.
- A poll worker will come to your vehicle and request to see an acceptable form of ID.

- The poll worker will return with accessible voting equipment on which you will cast your vote.

Look for the next issue of *disAbilities Celebration Connection* to be posted during the month of January, 2013. Send us story ideas, interesting links, and events. We can't do it without you!

*disAbilities
Celebration Connection*
is published by
Celebrating Special Children
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Burke, VA 22009

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Questions? Comments? Please use the **CONTACT US** form at www.celebratingspecialchildren.org

Links I Love~



The Projected Image: A History of Disability in Film

Editor's note:

Several months ago I wrote an editorial about my perceptions of people with disabilities in the movies and one of our writers, Gregg Donaldson, submitted an article on the same topic. I guess it probably is wishful thinking to imagine that Turner Classic Movies (TCM) got the idea from me! Nevertheless, I am pleased to see that TCM dedicated the month of October to exploring the ways in which people with disabilities have been portrayed in film. On behalf of **Inclusion in the Arts**, Lawrence Carter-Long joined TCM host Ben Mankiewicz for **The Projected Image:**



A History of Disability in Film. The special month-long exploration aired Tuesdays in October.

As part of the movie screenings, actors and other people in public life who have disabilities commented on the various movies; in some cases with admiration, sometimes with amusement, and sometimes even with scorn. Sometimes, the commentators said, they got right and sometimes they got it really wrong, especially, since in the earlier days of filmmaking, for example, it would have been almost unthinkable that a deaf actor would portray a deaf person, or a actor with Cerebral Palsy would portray a person with CP. One striking moment that Hollywood got it right was when Harold Russell, a non-actor who had lost his hands in WWII, portrayed the part of a serviceman who lost his hands, in **The Best Years of Our Lives** (1946).

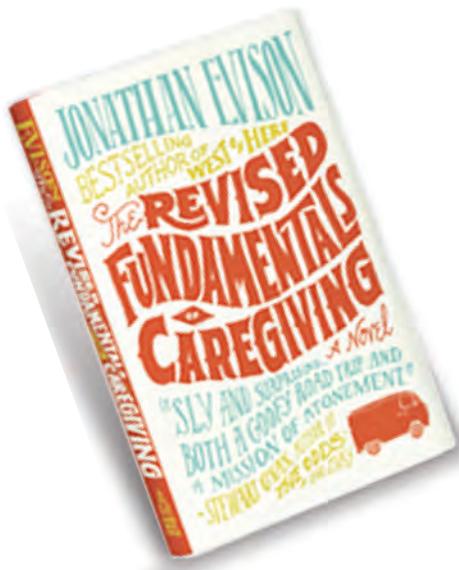
The following is a complete schedule of the films about disabilities that TCM aired in October. As you look down the list, you may notice that some of your favorites are missing. Maybe next year. ■

- **The Unknown** (1927)
- **Lucky Star** (1929)
- **Freaks** (1932)
- **Of Mice and Men** (1939)
- **Eyes in the Night** (1942)
- **Bedlam** (1946)
- **The Best Years of Our Lives** (1946)
- **Johnny Belinda** (1948)
- **Sign of the Ram** (1948)
- **Bright Victory** (1951)
- **Mandy** (1953)
- **Reach for the Sky** (1956)
- **23 Paces to Baker Street** (1956)
- **An Affair to Remember** (1957)
- **The Miracle Worker** (1962)
- **A Child is Waiting** (1963)
- **A Patch of Blue** (1965)
- **Charly** (1968)
- **Butterflies are Free** (1972)
- **One Flew Over the Cuckoo's Nest** (1975)
- **Gaby: A True Story** (1987)

About Inclusion in the Arts



Inclusion in the Arts advocates for full inclusion of artists of color and performers with disabilities at all levels of production in film, television, and theatre. The principal aim is to achieve full inclusion in American arts and entertainment, such that what we see on our screens and stages truly reflects the society in which we live; where each artist is considered on his/her merits as an individual; where the stories being told are drawn from authentic and diverse experiences; and where our individual humanity can be celebrated. For more information, visit <http://inclusioninthearts.org>



The Revised Fundamentals of Caregiving: Review and Musings

by Carrie Smoot

Don't expect a how-to guide for dealing with personal care attendants (and vice versa) in Jonathan Evison's new novel, *The Revised Fundamentals of Caregiving* (Algonquin Books). This was my first introduction to the author, and I really didn't know how I would feel about the story when I finished it. This is his third work of fiction.

Come to think of it, no such book exists that prepares people with disabilities to work with personal care attendants (PCAs). There are numerous local resources and agencies, workshops and articles on the topic, and whatever you can find out from talking with friends. And some people build resource files on independent living. A common question, even from strangers, is "What's your plan for independent living?" They may even make outright, "helpful" suggestions, such as, "You should be in assisted living or a group home." But individuals know what they prefer, and

decisions about living arrangements are and should be ultimately up to them. Very few people have no plan at all, but it's important to be flexible, because so many things can change over time.

Depending on the nature of someone's disability, at some point that person will need help from other people with the activities of daily living—in addition to assistance from family members and friends. Some common questions: What do you need help with? How do you choose the right people for the job? Do you want to manage your own PCAs, or work with an agency? Where do you go for information? How do you know you're making the right decisions? Sometimes, the tasks you need help with are embarrassing, but you have to ask for help anyway.

For some people, working with PCAs begins in childhood. Others need help as they age. Some attendants do their jobs well, but others, not so much.

It's a learning process, as others have told me, with a lot of trial and error. Medical information, nursing and emergency training, safety precautions, and so much more can be formally taught, but all the intangibles, such as trust, patience, caring, building friendships, setting boundaries, and adhering to schedules have to be worked on—especially the person with the disability, who is striving to do as much as he or she can independently.

These questions led me to the book.

Evison's characters are relatable and real, and the novel is set in the state of Washington. The details were sparse; reading it sometimes felt like solving a puzzle. The main character is Ben Benjamin, the novel's narrator, who is trying to rebuild his life after tragedy. Not knowing what to do with himself, and out of luck in the job market, he signs up for a course called "The Fundamentals of Caregiving."

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Eventually, he lands an opportunity with the county department of human services, and the agency sets up an interview with Trev, a nineteen-year-old young man with Duchenne muscular dystrophy, and Elsa, his mom, whom Ben says “deserves to wear a cape” for all that she does to care for Trev in addition to her other responsibilities. Long story short, Ben gets the job.

But no amount of class work prepares Ben for Trev, who has a huge chip on his shoulder. Each of them has to find his way in the process, and they eventually become friends. It seems to Ben that Trev isn’t motivated enough. He doesn’t want to go to college, is preoccupied with girls, watches too much TV, is fixated on routines, and thinks about many things that he will probably never see or do—in Ben’s opinion. He’s obsessed with the Weather Channel and unusual tourist attractions, and has Ben locate them on a map,

marking them with thumbtacks. Readers might wish that Trev was different, but Evison does a great job of making Trev a real person; that is to say, he doesn’t offset Trev’s disability with a saintly personality.

And then Ben gets the idea that he and Trev should go on a road trip to see all the things that

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Trev is curious about. Once they have overcome Elsa’s strenuous objections, they set off in Ben’s van. Along the way, they meet up with an unusual cast of characters. Who doesn’t love a road trip? But I’m sure this doesn’t happen in real life very often. Just sit back and enjoy this ride—one that is full of hope, heartbreak, struggle, and coping with what is—not what you would like things to be.

Along the journey, readers can

relate to Ben’s and Trev’s experiences, including ensuring accessibility of hotels and restaurants, the locations of hospitals and wheelchair repair places—all the little details you have to attend to when you travel. They have to deal with the consequences when access is lacking—even if it means entering a restaurant through the kitchen and ignoring stares from strangers as you are lifted in your wheelchair up “one little step.”

Readers empathize when Trev has to direct other people to do things for him, simply because he

can’t physically do them himself. Trev’s isolation also rings true, but you hope that as he gains more life experiences, he won’t be so isolated anymore. And you hope that for the other characters as well. ■

For more on the author, see the snippet below from the website www.jonathanevison.net.

Carrie Smoot is a Northern Virginia freelance writer.



Jonathan Evison says, “. . . I believe in the power of stories to transform. I still think the novel is the greatest empathic window ever devised by humankind, and I think it would be a better world if everybody read at least one novel per week. Way better than if they watched Mad Men. Or played Farmville. I have one theme: reinvention. I believe people can change. I believe most people want to. I believe in forgiveness, forbearance, generosity, and humor in the face adversity . . .”



BE ALLERGY SAFE THIS HALLOWEEN



Editor's note:

My thanks to Allergy & Asthma Network Mothers of Asthmatics (AANMA) and the Florida Center For Allergy & Asthma Care for this informational sheet.

Trick or Treating can be fun, yet spooky for parents of children with allergies and asthma. Triggers hide like ghosts everywhere, and not only in treats.

DEVILED MAKE-UP

Like all the invisible ingredients in a deviled egg, inexpensive makeup can contain ghostly allergens. Test the products in a small area of skin days before to avoid unpleasant surprises or unwanted reactions.

CREEPY COSTUMES

Storing last year's costumes in the attic can be a smart recycling and money-saving tip, but when reusing them be careful of mold, moths and dust mites. Make sure you clean them properly in order to rid them of any haunting allergens.

THE PUMPKIN PATCH

Ever heard of allergy to pumpkin? Although very rare, this can also prompt a serious allergic reaction in a child with a pumpkin allergy. Be very careful of accidentally unveiling this allergy while choosing your Jack-O-Lantern this Halloween. Be aware of mold, dust and spiders while at your local pumpkin patch or store.

THE SWEET & SOUR SIDE OF SUGARY GOODIES

READ THE LABELS for the most common allergy-inducing enemies: peanuts, tree-nuts, cow milk, soy milk, egg, sesame seeds, corn, wheat. And keep in mind it's not only allergies children must be mindful of, excessive amounts of their favorite candy corn, cotton candy, candied apples, chocolate bars and other tasty treats can send children straight to the dentist or worst, the Emergency Room.

HAVE A . . .

- **S**tay in a group when trick-or-treating through neighborhood streets.
- **A**void eating candy you're not familiar with and carry hand wipes in case of accidental exposure.
- **F**eel free to say "no thank you" to treats you are allergic to.
- **E**pinephrine, cell phone and emergency contact should always be carried in case of allergic reaction.

. . . HALLOWEEN!

Allergy & Asthma Network Mothers of Asthmatics (AANMA) is a leading nonprofit family health organization dedicated to eliminating suffering and death due to asthma, allergies and related conditions.

AANMA's core areas of expertise are education, advocacy and community outreach.

Education: AANMA's website, www.aanma.org, and flagship publications, *Allergy & Asthma*

Today magazine and *The MA Report* newsletter, are consumer lifelines to medical news and healthy living.

Advocacy: AANMA's annual Asthma Awareness Day Capitol Hill highlights critical issues that need national attention. Most recently, they led the campaign to ensure students' rights to carry and self-administer their lifesaving asthma and anaphylaxis medications at school.

Outreach: AANMA volunteers across the country work in their local neighborhoods to serve community needs. The Hispanic Outreach Program includes culturally competent Spanish-language materials and a volunteer network that works directly with underserved families. AANMA's work is always patient-centered, never endorses products or services and is often available for free.

Visit www.aanma.org



THE UNITED STATES
DEPARTMENT OF JUSTICE

Court Approves Comprehensive Agreement Between US and the Commonwealth of Virginia Regarding the Rights of Individuals with Intellectual and Developmental Disabilities

Department of Justice
Office of Public Affairs
FOR IMMEDIATE RELEASE Friday, August 24, 2012

The U.S. District Court for the Eastern District of Virginia has approved a comprehensive settlement agreement between the United States and the Commonwealth of Virginia, resolving the department's findings that Virginia's system for serving people with intellectual and developmental disabilities violated the Americans with Disabilities Act (ADA). The department had found that Virginia was violating the ADA requirement, as interpreted by the Supreme Court's decision in *Olmstead v. L.C.*, to provide people with intellectual and developmental disabilities the opportunity to live and receive services in the community.

As the court noted in its order approving the settlement agreement, it "addresses pressing needs" and "dramatically changes the way Virginia provides services to" individuals with developmental disabilities. The settlement agreement will provide relief to more than 5,000 people by expanding community services and supports, including Medicaid-funded home and community-based waivers, crisis services, housing and employment supports and by establishing a comprehensive quality management system. The court further found that the agreement "is completely consonant with the principles set forth in the ADA, as interpreted . . . in *Olmstead*."

The agreement is court-enforceable, and an independent reviewer with decades of experience will monitor the commonwealth's compliance with the agreement, meet with the parties and stakeholders, and issue regular reports.

The Justice Department and Virginia submitted the agreement for the court's approval on Jan. 26, 2012. On March 6, 2012, the court provisionally approved the agreement and solicited public comment on it. After considering hundreds of submissions from a wide range of stakeholders and conducting a day-long hearing on June 8, 2012, the court determined that the agreement was "fair, reasonable, and adequate" with limited modifications. The department and the commonwealth then submitted modifications, and on August 23, 2012, the court formally approved the agreement as modified and entered it as a court order.

"We are pleased that the court, after hearing from thousands of very engaged stakeholders and examining the extensive record, gave final approval to the settlement agreement," said Thomas E. Perez, Assistant Attorney General for Civil Rights. "We commend the commonwealth of Virginia, and particularly the leadership of Governor McDonnell and Secretary Hazel, on the commitment they are already demonstrating to fully implementing the agreement. We also appreciate the deep interest and involvement of stakeholders, including those who have long fought for these changes as well as those who raised concerns."

"We are committed to ensuring that the agreement is implemented fairly on behalf of all Virginians with intellectual and developmental disabilities," said U.S. Attorney for the Eastern District of Virginia Neil H. MacBride.

The Civil Rights Division enforces the ADA, which authorizes the Attorney General to investigate whether a state is serving individuals in the most integrated settings appropriate to their needs. Please visit www.ada.gov/olmstead to find the settlement agreement and fact sheet about the agreement, and to learn more about the division's ADA *Olmstead* enforcement efforts, and www.justice.gov/crt to learn more about the other laws enforced by the Justice Department's Civil Rights Division. ■

2012 National Health Observances

healthfinder.gov/nho/nho.asp

Source: 2012 National Health Observances, National Health Information Center, Office of Disease Prevention and Health Promotion, U.S. Department of Health and Human Services, Washington, DC.

November

American Diabetes Month

American Diabetes Association

www.diabetes.org/in-my-community/programs/american-diabetes-month/

National Family Caregivers Month

National Family Caregivers Association

www.thefamilycaregiver.org/national_family_caregiver_month/

National Epilepsy Awareness Month

Epilepsy Foundation

www.epilepsyfoundation.org

14-18 ~

Get Smart About Antibiotics Week

National Center for Immunization and Respiratory Diseases

www.cdc.gov/getsmart/campaign-materials/week/index.html

December

Safe Toys and Gifts Month

Prevent Blindness America

www.preventblindness.org/2013-prevent-blindness-america-eye-health-and-safety-observance-calendar

1 ~

World AIDS Day

World AIDS Campaign

www.worldaidscampaign.org/world-aids-day

2-8 ~

National Handwashing Awareness Week

Henry the Hand Foundation

www.henrythehand.com/news-events/national-handwashing-awareness-week/

EPILEPSY AWARENESS DAY

November 5 is Epilepsy Awareness Day

Sponsored by the Epilepsy Foundation of Virginia-Central Virginia Chapter

FREE

9:00 a.m. to 3:00 p.m.

Lewis Ginter Botanical Garden • 1800 Lakeside Avenue • Richmond

(804) 262-9887, ext. 300

For more information visit

www.epilepsyvirginia.org/index.php/epilepsy-awareness-day



*Please see the Calendar page of the Celebration Special Children website
for more upcoming calendar events.*



INCLUSIVE SCHOOLS WEEK

DECEMBER 3 -7, 2012

The Inclusive Schools Network is pleased to announce the 12th Annual Inclusive Schools Week will be celebrated December 3–7, 2012, in classrooms, schools, and communities throughout the world. Inclusive Schools Week™ (ISW) highlights and celebrates the progress schools have made in providing a supportive and quality education to all students, including those who are marginalized due to disability, gender, ethnicity, geography and language. It also provides an important opportunity for educators, students, and families to discuss what else needs to be done to ensure that schools continue to improve their ability to successfully educate all children. ISW is sponsored by the Inclusive Schools Network at Stetson & Associates, Inc.

This week celebrates how schools can make progress on their journey from “*Awareness to Action*” follow a path of reflection, planning and action. This year’s Celebration Kit contains updated resources to plan a successful Inclusive Schools Week™ celebration and includes new tools aimed at supporting schools in the process of becoming more inclusive.

The Celebration Kit is available for download at the extensive Inclusive Schools Network website at www.inclusiveschools.org. You may also purchase the Celebration Kit along with several other resources on a USB drive at the Inclusive Schools Network Shop- blog.inclusiveschools.org/shop.

Inclusiveschools.org has a fresh look and a wealth of innovative resources. It is the home of the Inclusive Schools Network and the place to find updated information about Inclusive Schools Week 2012 and to order new ISW products. Leading up to the ISW 2012 Celebration there will be weekly postings of ideas, events, and resources to support schools in planning their ISW activities.

For more information about the Inclusive Schools Network and Inclusive Schools Week, please visit www.inclusiveschools.org or email inclusiveschools@stetsonassociates.com. Be sure to sign up for Inclusive Schools Network News for regular updates as well as other news and information related to building schools and communities that are welcoming of all children and youth. ■

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Disability Support Services in Community Colleges

Approximately 45 percent of undergraduates with a disability are enrolled at public two year institutions, according to National Postsecondary Student Aid Study data (NCES, 2008). The American Association of Community Colleges (AACC) conducted a national survey in 1996 with support from the U.S. Department of Education to gather information about students with disabilities and the range of disability support services in community colleges. This report found that only half of the community college students who reported having a disability used disability support services (Barnett, 1996).

AACC conducted a similar survey in 2006 whose objective was to update the earlier information about staffing, services, and activities related to students with disabilities. Unfortunately, it garnered a disappointingly low response rate. Researchers surmised that the lack of a single point of contact at colleges for collecting data about students with disabilities could be the reason for the low response rate to the online survey. Although the findings from the survey were not statistically significant, some insights about staffing, services, and activities were gained from the institutions that participated in the survey.

The 2006 survey showed that community colleges were creatively meeting the needs of students with disabilities. Nearly three-quarters of the respondents reported having a dedicated office for disability service services; colleges without a dedicated office averaged only 2 FTE staff to support students with disabilities.

The top five disability categories for which community colleges reported services were:

- learning disabilities
- emotional or psychiatric condition
- orthopedic or mobility impairment
- attention deficit/hyperactivity disorder and
- health impairment.

The most commonly reported accommodations and services provided by community colleges were academic counseling,

note takers/scribes/ readers, testing accommodations, alternative media, and tutoring services.

Other disabilities reported in smaller numbers included the categories of developmental disabilities, deaf/hard of hearing, blind/visually impaired, and brain injury. Speech and language impairments, HIV/AIDs, and autism spectrum disorders were the least frequently reported categories of disability.

National data trends show that the reporting of learning disabilities grew significantly in the 1990s. Of those surveyed by AACC, the average number of students registered for a college's disability support services in that category was 111, twice as many as the other categories. The accommodations noted above reflect a concentration of resources for learning disabilities.

National data trends also show that students with disabilities are most commonly found in two-year institutions and in recent years completion rates for community college students with disabilities have increased from 11 percent in 2003 to 16 percent in 2007 (NCES 2004, NCES 2008).

The AACC respondents emphasized the crucial need for partnerships within the community, especially with high schools, rehabilitation centers, and vocational education institutions. Top activities of recruitment, academic success and post-collegiate goals reported include faculty and staff training on compliance with regulations of the Americans with Disabilities Act, transition services from high school to college, and disability awareness in the community. ■

Sources:

- National Center for Education Statistics. (2004). *National Postsecondary Student Aid Study 2003–04*. Washington DC: U.S. Department of Education. Available from the Data Analysis System Web site, <http://www.nces.ed.gov/das>.
- National Center for Education Statistics. (2008). *National Postsecondary Student Aid Study 2007–08*. Washington DC: U.S. Department of Education. Available from the Data Analysis System Web site, <http://www.nces.ed.gov/das>.

Editor's note: My thanks to the American Association of Community Colleges for this informational sheet. For more information, visit www.aacc.nche.edu. I did a bit of looking through the web to see if more current information was available and came across a publication from The National Center for Education Statistics (NCES), entitled **Students with Disabilities at Degree-Granting Postsecondary Institutions**, dated June 2011. To view the report, visit <http://nces.ed.gov/pubs2011/2011018.pdf>