KINDLE 2: TO TALK OR NOT TO TALK?
The World Wide Web is an essential resource for acquiring and providing information, enabling social interaction, enhancing education, assisting recreation, simplifying commerce, furthering governmental transactions, demystifying health care materials, complying with the United Nation’s human rights proclamation and much, much more.

The Web Accessibility Initiative (WAI) of the World Wide Web Consortium (W3C) has made it its business to make that resource accessible and able to provide equal access and opportunity to people of all abilities.

To that end, the WAI of the W3C has a Web Content Accessibility Guidelines Working Group that spent 10 years upgrading the original set of guidelines (WCAG 1) to keep pace with the rapid development of new technologies. The new version is called Web 2.0, or WCAG 2.0.

The good news is that those of us who aren’t very geeky or nerdy need not pay attention to the details of this specification. We just have to be able to tell whether the materials we encounter on the Web are accessible (particularly if we have problems with using a monitor or mouse) and report any difficulties in using the Web.

By focusing on the user’s needs, the standard that is now “official” assures that any designer who makes materials for the World Wide Web has a set of guidelines and associated examples enabling production of significantly more accessible Web content for everyone. WCAG 2.0 has established four principles, known by the acronym POUR: perceivable, operable, understandable and robust.

The first principle means that information must be presented to users in ways they can perceive. A site should be perceivable to everyone, even if users require assistive technologies such as screen readers or magnifiers to actually sense the content, either as text or through spoken text (or Braille).

If the content is aural, there must be various kinds of controls enabling the deaf or hard of hearing to comprehend the content of the sound and be able to scroll around while still getting a usable version of what “normal users” expect. Just as any images must have “alt-text” to replace them, so sounds must have visible versions of the content (or sight if not verbal) and videos should have “video description” so that actions onscreen are conveyed through spoken descriptions.

The second principle, operable, means that all functions should be available from a keyboard. Operable means that those who cannot routinely use a mouse have a way to interact with such things as forms, via the keyboard, or with sip- or puff-actuated switches or whatever assistive technology they need to deal with the Web and computers in general.

The next principle states that text content should be readable and understandable. Understandable is a bit more involved because users’ disabilities may include not only those of a physical nature but of a cognitive one as well. The material needs to be as simple as is suitable for the intended

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**Web Accessibility is Up to All of Us**

**By William Loughborough**

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**March 11th, 1993** – Janet Reno is confirmed as first U.S. female attorney general, under President Bill Clinton. After graduating from Harvard Law School in 1963, Reno was named staff director of the Judiciary Committee of the Florida House of Representatives in 1971 and accepted a position with the Dade County State’s Attorney’s Office two years later. In 1978, Reno was appointed state attorney for Dade County (now called Miami-Dade County), where she helped reform the juvenile justice system, pursued delinquent fathers for child support payments, and established the Miami Drug Court. In 1995, Reno was diagnosed with Parkinson’s disease.

**March 18th, 2003** – British Sign Language is officially recognized as a language. Although the United Kingdom and the United States share English as the predominant spoken language, British Sign Language is quite distinct from American Sign Language (ASL). BSL finger spelling is also different from ASL, as it uses two hands whereas ASL uses one. BSL is also distinct from Signed English, a manually coded method expressed to represent the English language. The sign languages used in Australia and New Zealand, Auslan and New Zealand Sign Language, respectively, evolved largely from 19th-century BSL and retain the same manual alphabet and grammar. BSL, Auslan and NZSL together may be called BANZSL. Makaton, a communication system for people with cognitive impairments or other communication difficulties, was originally developed with signs borrowed from British Sign Language.

**March 18th, 2005** – Terri Schiavo’s feeding tube is ordered removed by a Florida court. Judge George Greer, a Florida District Court judge, deemed a feeding tube to be an extraordinary life-saving medical procedure, even though Schiavo’s brain injury was not considered to be terminal. The request was made by her husband, Michael Schiavo, who won a 1992 lawsuit based on the argument that he would need money to continue her skilled care. This was the third time that Schiavo’s feeding tube was removed. In 2003, it was removed but reintursed after the Florida Legislature intervened and passed “Terri’s Law.” In 2005, the U.S. Congress met in an unprecedented session to try to save her life, but that effort was ultimately unsuccessful. She died on March 31, 2005. The doctor who conducted her autopsy stated that, based on the physical evidence, it would be impossible to determine what level of brain functioning existed.

**March 21th , 1985** -- Rick Hansen (born August 26, 1957) is a Canadian paraplegic athlete and activist for people with spinal cord injuries. Following a car crash at the age of 15, Hansen sustained a spinal cord injury that paralyzed him from the belly button down. Hansen is most famous for his “Man in Motion” world tour. He started his Man in Motion tour on March 21th , 1985 from Oakridge Mall in Vancouver. Although public attention was low at the beginning of the tour, he soon attracted international media attention as he progressed on a 26-month trek, logging over 40,000 km through 34 countries on four continents before crossing Canada. He returned to Vancouver’s BC Place Stadium to cheering crowds of thousands on May 22th, 1987 after raising $26 million for spinal cord research and quality of life initiatives. He was hailed as a national hero.

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**This Day in Disability History**

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**Continued on page 6**
Commentary

Reading Device Kindles a Controversy

By Deborah Kendrick

When Amazon first came out with the Kindle, a handheld e-book reader, people who were blind or visually impaired paid little or no attention. Then, on February 9th, the Kindle 2 was announced – and that, as they say, was a whole new ballgame.

Kindle 2, similar in size and lighter in weight than a typical paperback book, was designed like its predecessor to store electronic books and enable the user to read them, advancing pages to simulate the appearance of printed books of the paper and binding variety. But Kindle 2 also has on board a text-to-speech capability, making it possible for those unable to read the screen visually to hear it read aloud in a computerized male or female voice. With a treasure trove of 260,000 books of every genre (available for download at about $10 a book), newspapers, magazines, wireless access to Wikipedia and more, Kindle 2 was clearly a product worthy of some attention.

Better still, for people who are blind, visually impaired or who have learning disabilities or physical disabilities making the handling of conventional tomes difficult or impossible, here was Amazon launching a mainstream, affordable product at long last that could be accessible to all.

Then, the Authors Guild, a professional organization of journalists and authors, jumped into the ring. Audio rights, said Authors Guild president Roy Blount, Jr. in a New York Times op-ed piece, amounted to 25 percent of their profits, and a text-to-speech feature would enable people to get audio without paying for it. Under pressure, Amazon began to back down, saying maybe they’d just allow the text-to-speech to be available on titles with a book-by-book author permission.

Outraged by this clear move toward segregation in the marketplace, the National Federation of the Blind and 20-plus other organizations representing veterans, seniors, people who are blind, people with learning disabilities, and people with a host of physical or cognitive disabilities that render the handling of print difficult, mobilized to protest this act of exclusion, resulting in the Reading Rights Coalition. The group launched an online petition, that has thus far garnered thousands of signatures, and staged a peaceful demonstration on April 7th outside the Authors Guild headquarters in New York City.

Will Amazon succumb to the pressure and enable the text-to-speech on a book-by-book basis, thus segregating those with print-related disabilities once again? Or will it recognize that it has launched a product that could be accessible to everyone, with or without disabilities, and thus claims a higher profit for everyone? The jury is still out, but the real problem, it seems to me, is one of misinformation with regard to what this technology does and does not do.

As is the case with so many inventions that benefit all people today, the concept of talking books was originally conceived to fill a need experienced only by people with disabilities. Thomas Edison invented the phonograph record, initially, to create spoken-word recordings for blind people. Out of that marvelous invention grew the National Library Service for the Blind and Physically Handicapped, a division of the Library of Congress, and its renowned talking books program.

In the 1980s, the concept of audio books – print books recorded by professional actors and narrators – extended into the commercial marketplace and, suddenly, professionals with long commutes, stay-at-home parents with no time to sit and hold a book, and college students wanting to listen to a classic while doing something else discovered the joy of listening to the written word. The audio book industry has continued to grow – most notably with the launch of Audible.com, an online service that sells audio books that can be downloaded and played on a host of handheld MP3 players. (The Kindle 2, incidentally, will play these books as well.) Only a fraction of all books published are available in audio format, however, and many of those are abridged versions of the original.

For people who are blind, or who have learning disabilities or physical disabilities rendering the handling of conventional print books difficult, the audio book industry has indeed been welcomed. Even more so, however, has been the advent of text-to-speech technologies. Programs that convert the printed word to a computerized voice are available on computers, laptops, cell phones and a host of other devices – making these devices accessible to those unable to see or comprehend the information displayed on screens.

While this access has been a boon to education and employment, it is an alternative or extension of the visual information – not a separate medium. Listening
to an audio book "performed" by a professional narrator is one thing; authors should receive additional monetary benefit when those products are purchased. But listening to a book through a computerized voice is simply another way of accessing what is on the screen. There is no performance. There is no additional production cost. The file downloaded is one and the same, whether accessed via eyes or ears.

Given the choice, most customers -- if listening is their preferred mode of access -- will opt to purchase an audio book (one read by a human) rather than listen to a computerized voice generated by text-to-speech capabilities. The difference offered by the Kindle 2 is that the availability of books is made equal to all customers. Any book that can be purchased and downloaded by a Kindle 2 customer can who can read it on the screen can also be purchased, downloaded and enjoyed by one who cannot read the screen.

What the Authors Guild members fail to understand is that accessibility to all is not only the right thing to do but also the most profitable. If the millions of people with print-related disabilities can buy any book, any time that Amazon adds to its constantly growing e-book collection and read it via text-to-speech, more books will be sold. And, when those books are available as bona fide audio books, read by human narrators and thus creating a different product, everyone -- with or without disabilities -- will pay extra for those products, and the authors will get their share.

Deborah Kendrick is a newspaper columnist and senior features editor for AccessWorld.

**Disability Advocate Ellis Keeps Taking Next Step Forward**

By Kathi Wolfe

Independence Today is conducting a series of interviews with leaders of the disability rights and independent living movements. This issue features an interview with nationally known disability rights advocate Ethan B. Ellis.

Many people, when they reach the three-quarters of a century mark, just want to kick back. After years of full-time work, they're ready to reap the rewards of their labor -- to spend time with their families, travel, enjoy their hobbies, volunteer for a favorite cause, or at most, work part time. But few of us are like nationally well-respected disability advocate Ethan B. Ellis.

Retirement, even semiretirement, isn't on the radar screen for Ellis, 75. After more than 40 years in the forefront of grassroots advocacy at the local, state and national levels, he continues to work full-speed ahead for social change for people with disabilities and others devalued by society.

Ellis, who has cerebral palsy, is president and chief organizer of Next Step, an Edison, N.J.-based national disability organization committed to social, economic and political change. In addition, he teaches disability policy as an adjunct professor at the University of Medicine & Dentistry of New Jersey School of Public Health.

Ellis was born in New Brunswick, N.J., and graduated from Highland Park High School in Highland Park, N.J., in 1951. He graduated from Oberlin College with majors in political science and psychology in 1956 and earned a master's degree in vocational rehabilitation from New York University in 1958.

In the early 1960s, Ellis directed vocational services at the Bird S. Coler Hospital and later supervised curriculum development specialists at Mobilization for Youth, a demonstration community action agency on the Lower East Side of New York City.

In 1968, Ellis joined the staff of the New Jersey State Economic Opportunity Office, where he later headed a unit that provided technical assistance to local community action agencies and other anti-poverty programs.

In 1976, Ellis helped establish the first legal program for people with disabilities in the country at the N.J. Department of the Public Advocate. As deputy director of its Division of Advocacy for the Developmentally Disabled, he founded and was the first president of the National Association of Protection and Advocacy Services.

After leaving his public advocate position in 1985, Ellis worked as a consultant, directing the staff of the Governor's Task Force on Services for Disabled Persons in New Jersey and the Task Force on the Prevention of Developmental Disabilities in Delaware. He also served as a management consultant to the commissioner of Rehabilitation Services Administration of the U.S. Department of Education and organized support for the Americans with Disabilities Act in New Jersey and in Washington, D.C.

From 1991 to 2006, Ellis was executive director of the New Jersey Council on Developmental Disabilities. During his tenure there, with "vigorous advocacy from the council," Ellis said, New Jersey began to close

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Protester at the April 8th Reading Rights Coalition action at the Authors Guild headquarters.
Christopher Stephen is an Australian pioneer in electronic publishing. To help his sister, who has multiple sclerosis, maintain her joy of reading, he was motivated to expand the services that electronic publishing offers to people with disabilities. His company’s Web site is www.readhowyouwant.com, abbreviated as RHYW. He was interviewed by John M. Williams.

Q: What commercial benefits do you see in RHYW’s multiple publishing services?

A: There are many benefits including:

1. We can help level the playing field for people with disabilities. This means that less time is spent trying to acquire content or make it accessible.
2. We can allow individuals as they age to continue to participate with ease in an enriching activity.
3. We can help improve literacy by providing formats that will benefit struggling and reluctant readers.
4. We can help publishers meet legal requirements for providing accessible content.
5. And we provide publishers with a vested business interest for making their content accessible.

Q: Who benefits from your services?

A: Consumers, libraries and publishers will benefit from our services. Let me expand. There are two broad categories of consumers who will benefit from RHYW services:

Category 1 is those individuals who are unable to read standard-format books because of illness that affects their vision/eye control (MS, diabetes, macular degeneration, stroke, etc.). There are visual challenges such as blindness, low vision. Other disabilities are cerebral palsy and learning differences such as dyslexia. Lots of research shows that large print benefits dyslexics and students who are labeled reluctant readers.

This category of readers spans all ages but skews toward older people as age-related issues and diseases are the fastest-growing category segment of the visually impaired market. For validation of this, see the number of vision-related products on the market — magnifiers, etc., and catalogs and Web sites directed to this demographic.

Q: And the second category?

A: Category 2 is readers who prefer large print because it makes reading easier. They do not consider themselves disabled. They prefer large print. This is the market that Thorndike, Doubleday and other large-print providers serve and have served for many, many years. This is a proven market that is growing as the population ages. At the same time, this population is poorly served because only a small percentage of books are available in large print.

In addition, we will be addressing how to help people for whom English is a second language, and we will try to help busy people like researchers and academics to read and learn better by changing the format of books.

Q: How can you help libraries and publishers?

A: For the first time, libraries will be able to order books in the formats best suited to their readers, and they will be able to order shelf-ready books. And we are working on a library donation program where individuals and companies can give books to libraries and have the name of the donor and a message from the donor printed in the donated book.

Publishers will be able to do the right thing and make their books available in multiple formats (and comply with disability discrimination legislation) with little risk and no upfront cost and make some money at the same time, with little effort.

Q: What benefits are there to an individual without a disability who uses your services?

A: Most people who have tried our EasyRead large-print formats and who do not have a disability have responded favorably to the large print. The usual response is: “I can read this!” Publishers have been reducing font size on standard editions so that they can put more words on a page, thus reducing the amount of paper they need to print a book. The result has been smaller and smaller type, so that even readers with normal vision have difficulty reading many standard books.

The more I study reading, the more complex and personal it appears to be. It also appears that there are many more things we are likely to be able to do for people – help them to read better, faster, remember things better, pronounce words better and so on. Large type can do this for some people right now, and we are expecting to be able to do a lot more in the future. We have optimized the EasyRead by improving eye tracking, using a font that is very easy for people to recognize, and reducing hyphenation.

The DAISY formats will allow people to read and listen to text at the same time. We have “chunked” the text so that phrases are pronounced and highlighted. We will also be trying new ways to display the text with DAISY.

Q: How difficult is it to convince print publishers to provide your type of printing services?

A: In the beginning, it was slow and difficult getting books from publishers. But several factors are changing this; the business model is proved. We are now established and getting sales. The sales of eBooks, especially on the Kindle, have taken off. Hard times are making publishers realize that they need to change, and disability discrimination lawsuits in some jurisdictions have spurred publishers to act.

Q: What is the commercial future of RHYW?

A: We want to become the one-stop shop for accessible and personalized publishing – both for publishers and consumers. We want to work cooperatively with publishers, distributors, booksellers and disability support organizations so that we can educate readers and get the right edition to each reader. We want to work with reading researchers to expand our range of formats and understand better which format suits which reader and why.

Q: Are you the future of printing?

A: Personalized books do allow us to format books for specific printing machinery so we can print high-quality books on different printing machines, allowing us to
E-Publisher
Continued from page 5

I want RHYW to benefit people with disabilities so that they can have access to content just like everyone else in society. It levels the playing field in this area. People with disabilities will have access to a much broader range of content than is currently available to them in the current system. People with disabilities will be able to participate in the conversations about books that we take for granted in our communities and personal lives as they will be able to get the content in a more timely manner. Currently, the time lag on the NLS (National Library Service) providing a best-selling title in Braille in the library system is at best six months from publication, effectively shutting Braille readers out of the conversation with their sighted peers. As well, I’d like to see a greater dissemination of accessible formats in the public library system that will allow the library system to serve all of their patrons more comprehensively.

Q: Is there an age group that you think prefers your services rather than holding a book?

A: Of course, the baby boomers are now all getting older and many are using reading glasses. Seniors are the fastest-growing segment of the population, and many of them already need or prefer large-print books. We try to make our editions small enough so that most people can hold them. Readers who would prefer not to hold a book can read books on an e-book reader or a computer screen in PDF format. For other readers, we offer the option of DAISY, Braille or audio formats.

The choice we offer to people is to have it their way. We are offering a whole new concept in publishing which for the first time allows people to choose how they access their content. This is certainly the case for non-sighted individuals who either read Braille or listen to various audio formats of books. We give readers the choice of reading a book in 24-point type instead of having to use a visual aid such as a magnifier. We give other readers the opportunity to choose the format of a book that suits them at the same time that it is made available in standard formats.

Q: Are schools receptive to using your technology? If they are, how?

A: The schools are receptive to the practical outcomes of our technology -- books in accessible formats -- so that all students have access to content. The model we are pursuing is partnering with publishers to make their copyrighted content available in accessible formats. They are receptive, as content needs to be accessible in order to meet the textbook adoption requirements of the large public-school systems.

Schools are required to provide materials in accessible formats to meet the needs of children with learning differences and children with disabilities. Schools are committed to improving literacy and are always looking for new ways to aid struggling and reluctant readers. Assistive-technology departments in schools are spending enormous amounts of time, energy and money to convert books for students that we could convert more efficiently and with more choices in format for the students. We would like to begin working closely with schools to create accessible formats so that they can make better use of their resources for things like research and hands-on help for students who need it. Greater dissemination of accessible content in the school system will allow students with disabilities to get necessary course materials more efficiently -- another way the playing field will be leveled.

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John M. Williams, who coined the phrase “assistive technology,” has been writing about disability issues since 1978. He can be reached at jmmaw@verizon.net. His Web site is www.atechnews.com.

This Day
Continued from page 2

March 26th, 1979 – A cooling malfunction causes a partial meltdown of the reactor core at the Three Mile Island nuclear power plant, resulting in the release of a significant amount of radioactive into the air. The nuclear power industry claimed there were no deaths, injuries or adverse health effects from the accident, although a peer-reviewed study by Steven Wing of the University of North Carolina found lung cancer and leukemia rates were two to 10 times higher downwind of TMI than upwind, in addition to plant and animal chromosomal damage. Governor Richard Thornburgh of Pennsylvania oversaw the cleanup of the accident and mandated the evacuation of many affected areas. While serving as attorney general during the George H. W. Bush presidency, Thornburgh oversaw passage of the Americans with Disabilities Act. Thornburgh became a noted advocate for the rights of people with disabilities after his son acquired a form of brain damage as a result of an accident.

April 12th, 1945 – Franklin Delano Roosevelt, the 32nd president of the United States, dies in Warm Springs, Ga., from a cerebral hemorrhage. FDR, despite contracting polio, was a central figure of the 20th century during a time of worldwide economic crisis and world war. Elected to four terms in office, he served from 1933 to 1945 and is the only U.S. president to have served more than two terms.

-- Compiled from various sources by Mike Reynolds

Do you know of an important date in disability history?

Send it to Mike Reynolds at:
uppitycrip@gmail.com
Jack Wiler works in pest control in New York City, lives in New Jersey, and reads poetry in all kinds of places. He reads his work at high schools, festivals and conferences, and in bars, the site of poetry's late 20th-century revival, when open mic nights, spoken word and slam poetry breathed new life into the form.

Wiler’s poetry is conversational and frank, yet he chose not to address a significant part of his life in his writing for a long time. We spoke about this choice and other facets of his experience by phone in early April.

Q: I read that your latest book covers formerly verboten ground, the topic of HIV. Can you talk about why you didn’t write about that part of your life?

A: I’ve been bisexual my whole life, but I had a relationship that fell apart, and me and cocaine entered a long friendship. I started going to gay clubs and having unprotected sex. It was kind of like a death wish, really. I knew what I was doing, and I knew that it was stupid. I’m not a dumb person. I was ashamed to talk about that, and I think that the one element of HIV as opposed to a disability that is just handed to you is that you’re ashamed that you did things that caused you to be this way. Maybe somebody (who) is blind may think he’s being punished in some way for something that he did. I don’t know too much about that. But if you knew that you could get this disease, and you did it – people are already feeling shamed because they’re gay, and you add on top of that you’re an idiot and you’re not paying attention to your health, the level of shame is enormous, and so, no, I didn’t write about it. I alluded to it a little bit but not much. When I got better I decided I would never do that again. I’m a human being – you lie to yourself all the time, but I try not to. I try to be honest and clear about things.

Q: How does your health status play into your everyday life?

A: When I first got sick, after I got out of the hospital, I weighed like 70 pounds. I had PCP pneumonia -- this is fall 2001. My hometown is very small town, in southern New Jersey, near Philadelphia. It’s very beautiful: all Victorian homes, grass, all that crap.

Q: Your poems, the few that I’ve read, are very matter-of-fact, almost conversational. Do you think of writing as part of a conversation with an audience?

A: That’s my theory of what poetry is. It starts as a conversation between the poet and himself. He’s talking to himself, and then you give the poem to someone either in performance or on a sheet of paper, and that conversation can expand from groups of people. It’s a conversation that doesn’t have an ending. I don’t think the single poem is a conversation. The group of poems, the mass of poems, is the conversation.

Q: How did you get into writing?

A: When I was a senior in high school I was geek but a nascent hippie, so I decided to write poetry to get girls. It didn’t work. I took a few creative writing courses in college, and later, a friend I knew from school who thought my writing was good came to me and asked if I was writing. I said no, I didn’t have time. He said, ‘You always have time to write. You should go to a writers group with me.’ That writing group didn’t work out, but my girlfriend at the time was a beginning writer, and we went to another writing group with free wine and cheese, and as it happened four of the people in the group were professors in creative writing. Through that group I essentially got an MFA in poetry, and I learned how to edit my work and how to hear my work. This same guy also introduced me to the beginnings of slam poetry. He said, ‘Do you want to go to a poetry reading at the Nuyorican cafe? You get up on the stage and read your poems and drink at the bar.’ I said, ‘OK.’ I read out there, and I got a standing ovation, and I said, ‘I’m doing this the rest of my life.’

Q: Tell me about your life as an exterminator.

A: In terms of what are the issues of working at my job, how does HIV/AIDS impact me, I only think the really simple level your energy levels aren’t what everybody else’s are. Second of all, just like I guess diabetics, I have a number of ancillary problems that raise their heads during the course of the day. I have neuropathies in my feet and my lower legs. As a consequence, I experience odd moments of pain throughout the day. There’s medicine for it, but it seems kind of dumb to take a pill just to make the bottom of your feet feel good. I’m taking enough medication already.

I’ve been upfront from the beginning with my employer and the people I work with about my status. Everybody I work with knows I’m HIV-positive. That was a conscious decision. I decided that in a really reason I’d become ill was because I’d denied my status, and had I acknowledged it I might have sought medical care earlier, and I never would have developed PCP pneumonia. I made a series of stupid decisions, and when you bundle them together with denial, you have a recipe for disaster. I was cooking up a storm.

I do my job just fine. I have lapses of memory. Some...
President Barack Obama’s inner Washington circle is full of Chicagoans. Two in particular -- Arne Duncan and David Axelrod -- sounded alarm bells among Chicago disability activists when their appointments were recently announced.

New Secretary of Education Arne Duncan was the former head of the Chicago Public Schools. Catalyst Chicago, an independent newsmagazine that reports on education in Chicago, characterized Duncan’s special education record at CPS as “dismal.” A few days after his appointment as secretary, Access Living, Chicago’s Center for Independent Living, issued a press release criticizing him for cutting $12 million from the CPS special education budget and for other moves that showed disregard for students with disabilities.

Senior advisor David Axelrod was the brains behind Obama’s presidential campaign.

Axelrod, whose 27-year-old daughter Lauren has epilepsy, has said he has deep empathy for people living with disabilities. Lauren Axelrod is a longtime resident of Misericordia, a segregated community for 550 people with developmental disabilities run by the Roman Catholic Church. To local disability rights activists, Misericordia is a symbol of the antiquated 1950s institutional-charity model of long-term-care delivery.

Axelrod has expressed deep affection for Misericordia and has helped raise lots of money for it. Disability rights activists wonder how the advice he gives the president on long-term care will affect efforts to shift money away from institutions and into community settings.

Catalyst Chicago wrote, “One area where there was no improvement or reform under Duncan was special education.” According to the publication, half of high school students with learning disabilities drop out and fewer than 25 percent of CPS elementary-school pupils (and less than 10 percent of those in high school) receiving special education services met state standards in 2007.

Rod Estvan, Access Living’s education outreach coordinator, said of Duncan, “The needs of kids with disabilities just don’t click with him.” The Access Living statement, which Estvan helped write, said that the $12 million in special education cut was originally proposed to be $26 million.

“If the cuts had been implemented, an estimated 200 special education teachers and 750 special education aides would have been laid off,” the statement said. The amount was cut in half in the face of protests, but Estvan said there is still a subsequent shortage of aides. “A lot of parents are bitter about it.”

The statement credits CPS for budgeting $23 million annually from fiscal year 2009 through fiscal year 2012 to Capital Project Funds for Americans with Disabilities Act projects. “These projects will make numerous previously non-accessible schools available for students with disabilities and will allow some students, who would have been bused long distances, to attend schools in their own communities,” the statement said.

Estvan said a similar agreement negotiated with Duncan’s predecessor disappeared from the budget when he took over. Though a new agreement was eventually reached, Estvan said valuable opportunities to make school infrastructure more accessible were lost in the interim.

Since 1997, CPS has been operating under a consent decree born of a special education lawsuit requiring it to make greater efforts to place disabled students in the least restrictive environment. When a federal judge extended that decree through 2010, Duncan unsuccessfully tried to appeal that decision. Estvan said that was another example of Duncan’s “hostility” toward special ed.

From the outside, Misericordia looks like a pristine, Dickensian village nestled on Chicago’s far north. According to Kevin Connelly, Misericordia development officer, residents range in age from infancy to about age 62, and the most independent residents function at the intellectual level of a 14-year-old. “More often than not when they come here, it means they will be here for their entire lives,” he said.

Some adult residents work on campus, such as at the greenhouse, gift shop or restaurant. Some have jobs in the community and some go to day programs. There are a variety of living situations, but most adults live in the 12-resident, same-sex houses on campus, Connelly said.

“We want people to make their own decisions to the extent that they can,” Connelly said. But life at Misericordia comes with many of the restrictions of institutional life. Connelly said that all those who visit the residents have to come from a list approved by family or guardians. He added that some residents are allowed to leave the campus unattended, but they must always let someone know where they are going and when they will return.

No residents are married. Lois Gates, assistant executive director, said that, to her knowledge, none has ever expressed a desire to marry, but if any did, Misericordia would probably not be an appropriate place for them to live.

According to Connelly, those who work on campus earn minimum wage, but because the state deducts most of what they earn from what it pays Misericordia for their care, most of their pay goes back to Misericordia. The residents get to keep little of what they earn.

Misericordia’s executive director is Sister Rosemary Connelly, Kevin’s aunt. Rosemary Connelly is a vocal opponent of attempts to shift funding away from institutions. In the column she writes for Misericordia’s quarterly newsletter, that is a common theme.

In one column, she wrote: “When I listen to advocates who want every person with developmental disabilities, no matter how severe their disabilities, to live in isolated houses in neighborhoods, I shudder with fear. What will happen to individuals living in isolated houses when their physical needs become so demanding that no individual house would be able to provide appropriate care? Will they be ‘dumped’ in inadequate nursing homes?

“When the person is so severely disabled -- an adult functioning at a mental age of 12 months to 3 years of age -- will the four walls of the house become their world? Are individual houses able to provide the medical, nursing and therapeutic services some persons need? Legitimate questions which some advocates appear to ignore. I don’t question the sincerity of these advocates who are very frustrated because of the lack of funding for smaller residential services. But would it not be more prudent and realistic to be evaluating services on ‘quality of life’ rather than size?

“Misericordia is classified as a ‘large institution’ with all the negative connotations
its developmental centers, increased funding for educational and community supports, adopted family support legislation and launched the Governor’s Inclusion Initiative, a demonstration project that shifted control over resources to the consumers who use them.

Before joining Next Step in 2007, Ellis was executive director of the Alliance for Disabled in Action, an independent living center in central New Jersey. As a member of the center’s board of directors, he said that the alliance and Next Step are planning several collaborative projects.

“...if we’re not willing to fight for that magnitude of change, we are tacitly giving up our birthright to equality; we are acquiescing to living lives of discrimination, exclusion and poverty.”

Ellis and his wife, Janet Chiorello-Ellis, have been married for 10 years.

“...We were both born on November 25, she 32 years after me,” Ellis wrote in an e-mail. They have a 3-year-old son, Ethan James.

During a wide-ranging e-mail conversation, Ethan discussed his career as well as his views on life, people with disabilities, and political, social and economic change.

Q: Did you identify as someone with a disability when you were growing up? Did you try to pass (as non-disabled)? Were you in “special ed-segregated” classes in school? How did the other students react to you – to your disability?

A: I went to a private one until eighth grade. I was elected president of the student council in public high school and vice president of the student council in college and was active in a large number of extracurricular activities in both.

My disability was so obvious that I couldn’t pass, so I became a “supercrip.” But I never felt I really fit in. Sadly, I probably did and didn’t know it.

Q: How did you get involved with disability rights – with disability rights advocacy?

A: I got involved in the black civil rights movement in the early 1960s because most of the people I worked with at the rehab hospital in NYC were African-Americans. As a result, I drove to Washington, D.C., to join the ML (Martin Luther) King March in 1963. That led me to a job at Mobilization for Youth on the Lower East Side, a community action agency. The day before I went to work there, the (New York) Daily News front page charged that it had 50 communist employees. In all, I worked in the Johnson anti-poverty program from 1964–1976.

At that point, Congress established the DD P&A system (the protection and advocacy system for people with developmental disabilities). It was the first I had heard of a disability rights movement. I was hired by the N.J. public advocate that year, and I found myself right in the middle of it. When (President Ronald) Reagan tried to gut the 504 and P.L. 94-142 regs (regulations for the Rehabilitation Act of 1973 and the Education for Handicapped Children Act), I played a leading role in stopping him.

All this goes to prove my two rules about life: Half of life is just showing up; the other half is being in the right place at the right time. If you do the first often enough, you increase the chances of the second happening. Now that I’m 75, I’ve added a third rule: The longer you live, the better the chances that following the first two will make life interesting.

Q: How do you see the disability rights movement in relationship with other civil rights movements?

A: They’re all rooted in the basic desire to be recognized as human beings, to be included in society as equals. They copy strategies from each other and tailor them (to) their individual needs. African-Americans organize geographically because they’ve been ghettoized, women rely on numbers because they’re the majority, people with disabilities are disadvantaged because they are dispersed geographically as well as by class and have difficulty traveling, but it takes less of us to look like a crowd because of all the equipment we use. I don’t know that much about gay, lesbian (bi-sexual) and transgender tactics, but you can fill in the blanks.

Unfortunately, all of their efforts have failed for the same reasons: their failure to demand and gain social and economic rights, the rights to adequate shelter, food and water, free health care, economic security and intellectual development. Without economic and social rights, civil rights lose much of their meaning. It doesn’t matter if the restaurant is accessible if you can’t pay to eat in it. It doesn’t matter if you can vote if you just died from a disease that richer folk don’t get or are easily cured of.

This hypercapitalist society will give you your civil rights if you raise enough ruckus. They just throw you in jail on the way to victory. That’s what they did to King. But when he joined the Memphis garbage collectors’ struggle for economic equality, they killed him.

In this society, the divisions by class are much stronger than any resulting in differences in race, religion, ethnicity, gender or disability status. In every case, that division has stopped civil rights movements short of achieving the benefits we expected of them.

Demographic data bear that out. By every measure, African-Americans are worse off today than when the 1964 Civil Rights Act was passed. They are poorer, less well-educated, less well-housed, less healthy, more apt to be put in jail. On average, women are less well off by most of the same standards than when Title IX was passed. The same thing happened to people with disabilities after we passed the ADA in 1990.

The key words here are “on average.” Sure, some of us, very few of us, escaped into the middle and upper classes. That’s why I call us “the escapees.” Our escape was due to a variety of innate, accidental and arbitrary factors. After we escaped, our movements fractured along class lines because the “escapees” were the most likely leaders of the movement, and most of them were no longer interested. They got theirs and didn’t want to be identified with those they left behind.

Q: How did you get connected to Next Step? Is Next Step working in coalition with other groups?
Survey Shows Good Access is Good Business

By Cindy Powell

Marketing to people with disabilities (PWDs), their families and friends is profitable to businesses. According to the U.S. Census Bureau’s 2000 survey and the 2004 National Organization on Disability/Harris Interactive Poll of Americans with Disabilities, PWDs have $220 billion in annual discretionary income, the most buying power of any traditionally underrepresented group.

The largest minority group in the nation is the more than one in five Americans with a disability. According to the survey, 30% of the nation’s families have at least one family member with a disability, 73% of people with disabilities are heads of a household and 62% of PWDs say they spend their money at businesses that treat all customers and employees equally.

The Internal Revenue Service provides annual tax credits to qualifying businesses that are accessible to people with disabilities. Those accommodations include:

- The removal of architectural barriers in buildings or vehicles.
- Accessible reserved parking spaces.
- Curb cuts with accessible paths from the parking area to barrier-free entrances.
- Walkways at least 48 inches wide.
- Ramps.
- Wide doors.
- Accessible restrooms, drinking fountains, telephones and counters to accommodate people using wheelchairs.
- Elevators.
- Sign language interpreters for customers and employees who have hearing impairments.
- Readers or printed materials in alternate formats (e.g., Braille, audiotape, large print) for customers and employees with visual impairments.
- A job coach or co-worker to provide support to an employee with a disability.

According to the Harris poll, the hospitality industry receives a $27 billion yearly boost by providing accessible facilities. Four out of 10 American travelers are people with disabilities and their companions. Because 77% of people with disabilities have no children in their households, they have more discretionary income and free time for travel and leisure activities.

In addition, $13.6 billion is spent on 31.7 million trips each year by travelers with disabilities. Annual spending by travelers with disabilities is $3.3 billion in the airline industry and $4.2 billion in the lodging industry.

Fifty percent of Americans 65 years and older have a disability. By 2030, the number of Americans over age 65 will more than double. More than 70% of Americans will acquire a disability prior to reaching the age of 75.

The Disability and Business Technical Assistance Center (DBTAC), a national network of 10 regional resource centers, provides up-to-date information, referrals, resources and training on the Americans with Disabilities Act (ADA) to businesses, employers, government entities and individuals with disabilities, as well as media and news reporters.

For more information, call the Rocky Mountain ADA Center at 1 (800) 949-4232 or go to http://www.adainformation.org.

Cindy Powell is an information specialist for the DBTAC Rocky Mountain ADA Center.

Obituary

Martha Mason Remembered

Martha Mason, a woman who lived in an iron lung died early on May 4th. She had bested polio, once a pandemic disease, over 60 years of her lifetime after being told she wouldn’t live to her teen years. Mason, a most unusual world record setter, lived in an iron lung for sixty years, longer than anyone else.

One month shy of her 72nd birthday, Mason died early in the day at home in tiny Lattimore, S.C., where she had “lived above” her disease flat on her back for more than 61 years. Mason spent most of her life confined to an 800-pound, 7-foot airtight yellow tube that enabled her to breathe, though she could leave the machine for about an hour a few times a day when she was young. But several bouts of pneumonia in her 20s further weakened her already frail body. Mason had always said that she would not let polio beat her. Her life demonstrated that she meant what she said.

Martha Mason was 11 and in an Asheville hospital when she was told, “You’ll never walk again. You’ll never bathe or feed yourself again. You’re basically an excellent mind and an exuberant spirit locked in an inert body - a prison. Can you live with that?” “No,” began the answer, “but I can live above it.”

That dire diagnosis and defiant response came one year after polio invaded her body the same day her beloved, brother, Gaston, who died from polio, was buried.

She wrote in 2002, “As a youngster, in pre-polio days, I enjoyed sports and considered myself an athlete ... proud of my physical strength ... unusually self-reliant. Suddenly, I was an 11-year-old quadriplegic, I was not strong and I was completely reliant on others ..... I would not be a whiner, but what would I be? ... What she would be is a person who never met a stranger, someone who overcame any obstacle deterring whatever goal she set and an inspiration whose influence will live on in the world.

This amazing woman and her iron lung completed high school and attended Gardner-Webb College. She attended Wake Forest University the same way. She graduated first in her class and earned Phi Beta Kappa honors. Using a voice-activated computer at home in Lattimore, she wrote her memoir, “Breath, Life in the Rhythm of an Iron Lung.” Martha has said, “I think I was born with supercharged, competitive genes. I always expect to win the gold.”

Actually, Martha Mason has spun for us all a golden legacy of human will trumping adversity. From her home on Oak Street, Martha Mason reached into the lives of people across the country and even the world.

Mason told an ABC News reporter just before her 71st birthday, “My story’s been one of joy, one of wonderful experiences. It has not been perfect. But that’s what people need to understand - that I have had a good life.”
Dear Advocates and Friends,

We are facing monumental change – a new Congress, a new president, and new leadership for NCIL. We have the opportunity to bring our movement out of the shadow of others. We have allowed ourselves to become invisible. We have allowed government to control our services and lives. We have allowed them to marginalize independent living by reinterpreting our law, diminishing our funding and failing to properly measure and report our accomplishments.

We must not sit and wait for change. We must focus on effectively promoting independent living to policy-makers and appropriators. We must communicate the value of our movement and our people.

The independent living program belongs to the people, not to bureaucrats and bean counters! It is time for us to take it back. This year's annual conference, Believe: We Are Better, Re-energize, Reorganize, Reauthorize! (June 5th to 8th at the Grand Hyatt in Washington, D.C.), is designed to give us the tools to do just that. It is an acknowledgement that our time has come. It is a proclamation that we will no longer allow narrow-minded “professionals” to impede independent living. It provides individuals with disabilities, centers and SILCs across the country a unifying opportunity to confront our common enemies: complacency, cynicism and resignation.

In 1986, Justin Dart testified before Congress that the Rehabilitation Services Administration’s vocational rehabilitation system was “a vast, inflexible federal system which, like the society it represents, still contains a significant portion of individuals who have not yet overcome obsolete, paternalistic attitudes about disability.” We have made inroads, but we have yet to seize control and turn it in a progressive direction.

As a community, we will insist that decisions be made with us and by us. We will re-energize our efforts to reauthorize the Rehabilitation Act, and we will insist on reforms that reflect the values of our community. No longer will “rehabilitation” programs exclude people with disabilities from deciding how our lives ought to be lived. We will design, implement and monitor programs that will be focused on the principles of independent living: civil rights, consumer control, and social, economic and political equality.

The doors of opportunity do not slam open; our common commitment and effort must make it so. We must believe in our ability to create change, to do that which has seemed impossible. We have little to lose and much more to gain in this time of critical change. We cannot stand in our own way. We need to put aside our internal differences, skepticism, and pessimism to re-energize, reorganize, and reauthorize, for our common goals and our shared vision.

YOU may register at: www.ncil.org.

It is my sincerest hope that you will join us for this weeklong event, especially during this crucial time for our community. The 2009 NCIL Annual Conference will be an opportunity to reinforce the resolve that will be needed during the coming years. In addition, it’s June in our nation’s Capitol - great weather, great times and great friends. I can’t wait to see you there!

Sincerely,

John A. Lancaster, Executive Director

NCIL Disability Policy Summit, Congressional Briefing and Hill Visits

On March 23rd, NCIL held a disability policy summit in Washington, D.C. Representatives from 22 national disability organizations attended. The NCIL Board presented its 2009 legislative and advocacy priorities. “The meeting provided a great opportunity for organizations to share their legislative priorities and engage in dialogue to continue collaboration,” said John Lancaster, the organization’s executive director.

The following day NCIL held its third annual congressional policy briefing in the Russell Senate Office Building. The NCIL Board of Directors worked to educate members of Congress and their staffs about independent living and our legislative and advocacy priorities. Tim Sheehan of Wisconsin gave an overview of CILs and SILCs. Jeff Hughes spoke about the Reauthorization of the Rehab Act, and Lou Ann Kibbee talked about the Community Choice Act. Several congressional staff members attended, and our policy priorities booklet was distributed to all.

Later that day, NCIL policy fellow Jason Beloungy attended a meeting with NCIL Board President Kelly Buckland, NCIL board member Tim Sheehan and Kelly’s wife and son Merle and Rodney, respectively. They attended a scheduled meeting with the chairman of the House Appropriations Committee, David Obey (D-Wis.) to talk about concerns with RSA not releasing information or funds related to the American Recovery and Reinvestment Act for the IL program, as well as the 2010 budget process.

The meeting was very positive, and the delegation felt good about what had been discussed in this face-to-face meeting with the chairman in his U.S. Capitol office. The chairman of the House Appropriations Committee is one of the most powerful members of Congress, and to get a personal meeting with him in his Capitol office is a very rare opportunity.

“The chairman’s office is located next to the office of the Speaker of the House and is not part of the Capitol tour,” Jason said. “Once inside the office, you had one of the best views. The view overlooked the National Mall and the Washington Monument. All of us in the room felt that this was an exceptional moment that none will likely forget.”

Jeff Hughes and NCIL staff Elizabeth Leef met with the lead staff person for Rep. George Miller (D-Calif.), chairman of the House Energy and Labor Committee, who is working on the Reauthorization of the Rehab Act. Recent events regarding RSA and the stimulus funds were discussed.

NCIL board members Mary Margaret Moore and Steve Higgins attended a meeting with the lead staff person for Sen. Ted Kennedy (D-Mass.), responsible for the Reauthorization of the Rehab Act on the Senate side. The Senate will be working from the old Senate version of the Reauthorization; the House wants to start from scratch.

NCIL will keep the membership informed and up-to-date as we learn more. NCIL will reach out to the membership for input on the act.

NCIL Continued on page 14
A: I’ve been a board member of Community Access Unlimited for 20 years. It’s a progressive agency that serves people with developmental disabilities and disadvantaged youth. Five years ago, the board concluded that providing services would never be enough to include people with disabilities in society as equals; that would require restructuring the political economics of the whole society, the kind of radical change that only social movements bring about.

They decided that people with disabilities should be part of such a movement, put up some seed money to make that happen, and asked me to lead the effort.

Q: What impact do you think Obama’s presidency will have on people with disabilities? What promises to individuals with disabilities has Obama made? What promises (to the disability community) do you think the Obama administration will keep?

A: Until we change the social, economic and political structure of this country, none of us who belong to devalued groups will be able to live with pride as equals in it. That is the magnitude of the change it will take.

If we’re not willing to fight for that magnitude of change, we are tacitly giving up our birthright to equality; we are acquiescing to living lives of discrimination, exclusion and poverty.

Viewed through that reality, we should not expect anything substantial from either major political party; they are both bought and paid for by economic interests whose only interest in us is whether they can make money off of us. We are not real people to them and to the politicians they own.

Obama is no exception. He is only the lesser of two evils. It is symbolically cool that he is black, but he is an “escapee,” willing to leave the rest of us behind to make it big in a class he wasn’t born in.

Obama’s disability platform contains the usual liberal promises: signing the U.N. Convention on the Rights of People with Disabilities, full funding of IDEA (the Individuals with Disabilities Education Act), more jobs in the federal government and so forth.

During the campaign, Obama declined to speak to disability groups like he did with other special interest groups a fraction of our size, and he only consistently acknowledged us in his speeches during the last two weeks of the campaign, despite aggressive urging from me and other members of his Disability Policy Advisory Committee. In short, he did not recognize us as an organized political bloc despite our numbers.

I think he’ll do for us what his liberal views and the state of the economy allows, but I don’t expect much more. That’s scary because the lousy economy may tie his hands, and when the economy goes south, discrimination against us and other minorities usually rises as the majority draws in on itself in fear.

Q: Even though you don’t see much hope in Obama or political parties, you still want people with disabilities to stick with the fight?

A: Of course. People with disabilities must keep fighting for our social, economic and civil rights. Our other choice is to become vegetables. The first step is to become politically active – register, vote, agree on a platform, support candidates — do whatever it takes to become recognized as a powerful political bloc. Then we must build local, state and national power through coalitions with others with whom we have common objectives: the poor; racial and ethnic minorities; women; lesbian, gay, bisexual and transgender people. Our struggle is all about combining principles with power. It will take both to turn society upside-down and shake it until it lets us in to live with pride as equals.

Q: What can independent living centers do to try to get folks with disabilities, who often are living in poverty, involved in the political process?

A: I have no expectations from independent living centers. Most have become too much like traditional service providers and are too dependent on “the man’s” money to bite the hand that feeds them. Organizations like Next Step will have to fill the breach.

Q: Why is it so important for people with disabilities to speak for themselves rather than have (non-disabled) professionals (people working in the field of disability) speak for them?

A: Most professionals don’t want for us what we’d choose for ourselves. They make their living off of our dependency and would be out of a job if we got what we really wanted.

Q: Have any historical or political figures influenced you in your advocacy work and thinking?

A: I worked closely with the late renowned disability rights icon Justin Dart Jr. and grew to respect his integrity. Theoretical and practical political economists have greatly influenced my thinking. Karl Marx laid the groundwork for much of that thinking – not the straw man we’ve been attacking for almost a century, but the humanist philosopher who said toward the end of his life that he wouldn’t have ever been a Marxist, so much had both sides debased his thinking.

Q: You may not want to talk about this. But if you feel like sharing, would you talk about your struggle with alcoholism? How did this struggle and your becoming sober impact your life? What are your thoughts about alcoholism – addiction – and people with disabilities?

A: I started drinking when I was 23 and discovered almost immediately that I was good – too good – at it. I was an active drunk for 15 years and quit in 1974 and had one drink a year later to quiet a gall bladder attack. That scared me worse than the pain, and I haven’t had one since.

I think it’s important that I talk about this freely, and I do. Studies show that substance abuse, including alcoholism, is higher among “crips” (people with disabilities), than it is in any other group, including Native Americans. And so is suicide. Our dependence on others who we can’t offend makes us turn our anger inward, against ourselves. We’re addicted to self-destructive behavior. That’s a major issue we’re trying to solve in Next Step. We can’t change the world with broken people; we have to heal ourselves because nobody else will. Our movement depends on it.

Q: What makes you keep going with advocacy at a time when you could just be enjoying yourself?

A: I have no choice. If I went fishing, all the prejudices I’ve been fighting would just go with me. Besides, I enjoy a good fight.

Q: But how do you keep from getting burned out?

A: I find life endlessly engaging. At my age, a new book or idea will make me rethink everything! My 3-year-old son is a wonderful gift who keeps me young.

(For more information, go to www.gonextstep.org.)

Kathi Wolfe is a writer and poet. She writes extensively on disability and other socio-cultural issues.
Poet Continued from page 7

are just because I’m getting older, but I don’t think a man of 52 should have to (be organized when) taking a shower so he doesn’t forget to shampoo. I think I have memory issues as a result of the severe weight loss. I could be wrong about that – there’s no medical data to support that – but I’m going to say that what I think I felt is true.

Q: How do you feel about HIV as a disability?

A: It’s a disability, but it’s an odd disability. It’s a disability mostly in your head. I take some pills, I go to work and I come home. Sometimes bad things happen. You go to the bathroom in your pants on the subway train, but that doesn’t happen that much, and for the most part, you can plan for (it). You can lay out where all the pit stops are throughout your day.

In this country, AIDS is probably the one disease that manages to merge both sexual shame and the shame of the disease with social punishment. There’s a consequence to not being honest with yourself, and the consequence is you become ill and you could die. It’s true that everybody’s going to die, but you could die much sooner than you normally would have. People do look down on you if you’re blind or in a wheelchair, and they think you’re not able. You’re not looking at the real person and talking to the real person. Some people respond to (this and their) disabilities by becoming not able. Some people say, ‘I want to be the guy who sits in the house and never goes out.’ Other people don’t. I don’t think it makes you a hero to say that you don’t want to sit in the house and that you do want to confront the world.

Q: What a great thought.

A: To me, I think more people would want to confront the world if there were (fewer) barriers. When I was first diagnosed I thought I couldn’t get medication because I didn’t have health care, but it turns out that in New Jersey, if you make less than $47,000 you can get health care. But the state never says you can get the medication. They don’t say that out front. They’re not really providing all the information they should to empower people to protect themselves and save their lives ‘cause they don’t want to say they condone this kind of behavior. Why couldn’t the health care worker who came to tell me I was HIV-positive (in the hospital) tell me, ‘You should go to this clinic, and you can get the medications and you can prevent your being sicker’? Instead she just said, ‘You’re HIV-positive,’ and pretty much, ‘Have a nice day.’

Is it a sin if you drink bad water in Mexico and get dysentery? Because you didn’t listen to somebody when they said don’t drink the water? That seems crazy. On the other hand, getting very sick made me religious, so I can’t really bitch too much.

Everybody in some way is disabled in a weird way, just like everybody’s sick every day. Your body is constantly being attacked by germs and viruses, and your immune system repels them. There are things that make you disabled in ways you would never think of, and yet we go through our days. I think we look at people with obvious disabilities and think they are less able to cope than others, but I think, in fact, that many people with disabilities are more able to handle the tasks they have to work harder at doing everyday things. They’re not better people necessarily. A lot of the people with AIDS that I worked with were not particularly nice, but they found ways to be in the world, (and) one thing a lot of them did have, and that I hope I still have, is compassion.

The Poem Where I Say Thank You came from a woman who worked at the office. She had two kids. She had really severe neuropathy. She could barely walk, and I was complaining that we were being paid slave wages, and she said, ‘You know, Jack, you’re full of it; you would do this work for free.’ And she was absolutely right. That springs directly from that experience. It’s my favorite poem.

(Wiler’s poems can be found on his Web site, www.jackwiler.com.)

Amy Halloran, a writer, lives in upstate New York with her sons and husband.

Obama Aides Continued from page 8

that implies. No matter, big is bad and thus, for some advocates Misericordia is not only bad but a ‘stumbling block’ for them to continue their ‘crusade’ to eliminate all residential services that are big. We ‘weaken’ their efforts because anyone who visits us knows that our children and adults are truly some of the happiest and contented people you would find anywhere. They are living lives of dignity, respect, challenge and beauty. Let’s pray for all our government officials that the Lord may touch their hearts and the weakest among us will be considered as they establish their future priorities.

Lawyers representing Misericordia residents and people on its waiting list have repeatedly tried to intervene in a long-running Olmstead lawsuit that seeks to create a greater variety of smaller community care options in Illinois. They argue that such a shift in priorities would take away their clients’ freedom to choose to live in places like Misericordia. The judge has repeatedly rebuffed their efforts.

Rosemary Connelly is not shy about courting powerful politicians. On January 12th, Axelrod was the guest of honor at a $500-a-plate fund-raising breakfast at Misericordia. The nearly 400 attendees, according to the Misericordia newsletter, included “a plethora of Illinois elected officials,” including the attorney general and state treasurer, the president of the Cook County board and four members of the Chicago city council.

“Of course,” Rosemary Connelly wrote in her newsletter column, “I had to use this gathering of many influential people to share my concerns … some sincere advocates -- on both the national and state levels -- would like to see communities like Misericordia closed solely because they are big.” After a tour of Misericordia at the Axelrod event, Rosemary Connelly wrote, “several state legislators shared that we should be a model for the entire country.”

Attempts to contact Duncan and Axelrod for this article were unsuccessful.

Mike Wier is a member of American Disabled for Attendant Programs Today, a group that works for the civil rights of people with disabilities. He is a frequent contributor to Independence Today.

For a complete news roundup, go to:
www.itodaynews.com

News Briefs
supplied by David Reynolds
from Inclusion Daily Express.

www.InclusionDaily.com
Board members Jeff Hughes and Carla Lawson met with Senator Colburn’s staff and discussed recent events with RSA. The senator’s staff will be contacting RSA on behalf of NCIL to see why IL funds are being held up.

In Congress, NCIL staff members visited the offices of Senators Lincoln (D-Ark.), Casey (D-Pa.), Hagan (D-N.C.), Roberts (R-Kan.), Markowski (R-Alaska), Hatch (D-Utah), Udall (D-Colo.), and Bennet (D-Colo.). In the House, the staff visited Representatives Tiahrt (R-Kan.), Jenkins (R-Kan.), Moore (D-Kan.), Chairman David Obey (D-Wis.), Moran (R-Kan.), Miller (D-N.C.), Tierney (D-Mass.) and Chairman Miller (D-Calif.).

Community Choice Act 2009 - Like Wings On An Eagle: Our Time Has Come!

Following the NCIL congressional briefing, a press conference was held in the Dirksen Senate Office Building, and the Community Choice Act of 2009 was introduced. Mike Oxford of Kansas ADAPT moderated the event, at which Sen. Tom Harkin (D-Iowa) and Congressman Danny Davis (D-Ill.) announced that they have introduced the Community Choice Act in the 111th Congress.

Our community showed up in force, filling the hearing room and the hallways outside. Disability rights activists from across the country participated in person and by phone from more than 100 sites nationally. Speakers included NCIL Executive Director John Lancaster, Dawn Russell of ADAPT, Andy Imparato of the AAPD, Marty Ford of the Coalition of Citizens with Disabilities (CCD), Victor Robinson of Self Advocates Becoming Empowered (SABE), and Mitch LaPlante, researcher at the University of California, San Francisco.

After Mike Oxford warmed up the crowd, Senator Harkin gave a rousing speech, emphasizing “our time has come.” He praised President Barack Obama for his support of the CCA and vowed that it will pass this year, either as part of broader health care reform or as independent legislation. Representative Davis then spoke about the pride he felt being connected to the Community Choice Act and said that the best advocates in the country are people with disabilities. He praised Harkin for his tireless efforts and quoted a Bible passage that emphasized Harkin’s continued efforts to pass the CCA over the past 17 years: “Those that wait… shall renew their strength. They will mount up, like the wings of an eagle …”

Lancaster testified that NCIL was there to collaborate in solidarity with everyone who was there to support the CCA. He said that the CCA is clearly one of the most, if not the most, important issues in our community. Many members of the NCIL Board of Governors and people representing centers for independent living were present at the hearing. Those board members not present were at that very moment visiting their congressional representatives, pushing for passage of the Community Choice Act.

Said Lancaster: “I want you folks to know that we are working this, and we will work it with you. I was struck by Mitch’s comment about CBO’s previous fear about people coming out of the woodwork to get benefits under the Community Choice Act. That’s such poppycock, and we all know it. How many people are going to come out of the woodwork to have someone help them go to the toilet or to pull on their underwear or to get in bed? Come on, let’s be real here. These are very personal services, which for some people are essential for them to participate fully in the community and even have a chance for a job and be productive, contributing members of their communities and of our great American society. And it’s a damn shame that people have to check themselves into a nursing home or a state institution just so that they can get the basic supports that they need to exist with no control anymore over when and how those services are delivered, no choice over who is delivering them. This is a matter of basic human dignity as well as rights. And it’s time for the status quo to end!”

Dawn Russell of ADAPT testified that the CCA is the most important bipartisan disability rights legislation of our time and that it must continue to be a top priority for Harkin, Davis and our community as a whole. “We have a window of opportunity; now a fresh breeze of hope and change are blowing through it,” she said. “Pick up your tool of choice and get to work!”

Marty Ford of the CCD testified that the institutional bias continues and waiting lists for community services continue to impede independent living. She noted that people with disabilities need to be included in health care reform and that the CCA is the solution and now is the time.

Mitch LaPlante of the UCSF testified about his research, outlining the need for the CCA to be restored by the Congressional Budget Office and the realistic cost of the bill. He agreed with Senator Harkin that this national problem needs a national solution.

Victor Robinson of SABE announced the organization’s support of the CCA and offered a personal account of the need for the legislation. “Why do people have to wait so long just to live in the community, close to their family and friends?” he asked. “We must change that, and we will!”

Andy Imparato testified to the civil rights aspect of the CAA and said that the promises of the ADA, independent living, and the ADA Amendments Act could never be a reality without the CCA.

What CILs and SILCs need to know about the American Recovery & Reinvestment Act (ARRA)

As we move forward in the 111th Congress, it is critical that we demonstrate the power of the grassroots independent living movement. We will secure full civil rights for people with disabilities and create a world in which people with disabilities are valued equally and participate fully!

The NCIL staff and board have been in constant contact with RSA, waiting for answers to our questions on the stimulus act (the ARRA). RSA has been telling NCIL they will have paperwork describing how much each state will receive and how soon.

The following questions have been submitted to the Rehabilitation Services Administration, along with NCIL recommendations.

1. When does the funding become available? Once available, is it subject to the same provisions as Part C, such as not having the ability to carry over funding?

NCIL recommendation: Due to the pressing need to expend funding within the existing year, and due to the fact that we are almost halfway into fiscal year 2009, we suggest allowing flexibility with ARRA funding so that it can be carried over into the following fiscal year. Most CILs will have the capacity and infrastructure to utilize the funding over a full fiscal year, but some may have difficulty in expending their allocation in a short period.

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of time. Therefore, waiving the carry-over restrictions for FY 09 and 10 would ensure the proper and efficient expenditure of funds.

2. How can a CIL that does not receive Title VII Chapter 1 Part B or C funding apply to receive funding?

NCIL recommendation: Assuming that the CIL meets the standards and indicators as described within Section 725 of the Rehabilitation Act of 1973, as amended, ARRA funding for Title VII Chapter 1, Parts B, C, and Chapter 2 is subject to the goals set forth within a state’s approved state plan for independent living (SPIL), which should also include a priority for the distribution of new funding. RSA will ensure that monies are distributed accordingly.

3. In states in which state money exceeds federal allotment (723 states), will the funding be distributed through the Designated State Unit (DSU)?

NCIL recommendation: Yes.

4. Is the funding restricted to a particular service?

NCIL recommendation: ARRA funding allocated through Title VII Chapter 1 Part B and Chapter 2 will be subject to the goals, objectives and priorities established within the state’s SPIL. ARRA funding allocated through Title VII Chapter 1 Part C will be subject to the center’s approved budget.

5. Will Part B and C funding allocated through the ARRA be required to be consistent with SPIL?

NCIL recommendation: Yes. See numbers 3 and 4.

6. Several states have reported a reduction in the appropriations to CILs because of the ARRA. Because of such, there is little benefit in receiving ARRA funding despite its intention “to stabilize state and local government budgets in order to minimize and avoid reductions in essential services and counterproductive state and local tax increases.”

NCIL recommendation: A maintenance of effort clause or regulation be implemented so that states do not reduce the amount of state appropriations to CILs.

7. Can NCIL, RSA and ILRU develop training and technical assistance designed to assist SILCs in claims?

NCIL recommendation: Yes.

8. Can NCIL, RSA and ILRU develop training and technical assistance designed to assist CILs in entrepreneurial activities?

NCIL recommendation: Yes.

9. Will ARRA funds be distributed according to the current funding formula for Title VII, Part B and C funds?

NCIL recommendation: Yes.

10. How can I calculate how much money my organization will receive?

NCIL recommendation: ARRA funds will be distributed according to existing formulas and SPIL recommendations.

11. In the unfortunate event that a state refuses to follow guidance provided within the SPIL, should a grievance procedure be included within the letter?

NCIL recommendation: Yes. The guidance should also be uploaded on RSA’s Web site for reference purposes.

12. Can ARRA funds be used for capital expenses?

NCIL recommendation: ARRA funding can be used in accordance with the CIL’s and SILC’s approved budget.

13. How will ARRA funded activities be monitored?

NCIL recommendation: ARRA funding should be monitored and reported through the existing Annual 704 Report.

14. Is a state match required for Title VII Chapter 1 Part B?

NCIL recommendation: ARRA funding is not subject to state matching requirements.

Compiled by NCIL staff

Web

Contd from page 4

purpose of the material. Someone doing a treatise on esoteric nuclear physics or mathematics cannot be expected to have to write it so that I can understand it, but if the site is to enable users to acquire information about SSDI benefits, for example, then it should be clear what it is trying to convey. It also must be clear how to move about on the Web site. This is usually referred to as “navigation” and might involve the use of a “site map.”

The fourth principle, robust, states that a Web site designer should assure compatibility with users' assistive technology.

Robust may be the most technical of the principles because it deals with the use of various current and evolving technologies. It all hinges on the notion of “interoperability” as a fundamental characteristic of accessible Web content. In short, if one’s access system doesn’t work like it’s supposed to, it is not robust.

The technologists have done their part. Now the rest is up to us.

What is our part in making the Web accessible? We are the monitors, judges and whistle-blowers whose job it is to actively advocate for our needs to use the same Web that so-called “normal” people do. When we encounter a problem with a Web site, particularly if it’s a governmental (.gov) or educational (.edu) presence on the Web, it is up to us to do what’s necessary to assure compliance with the principles.

Schools and governments (local, state and federal) are required to conform to the guidelines. It’s the law.

What can we do when we encounter a site that doesn’t
comply? If it’s a government site, it probably adheres to the guideline requirements that call for it to clearly identify where to register a complaint about accessibility.

If they ignore you, ramp it up – even if you have to notify your representative of the site’s failure to respond. When such efforts fail (which they often do), send me a report, and I will take action, starting with the same things you’ve tried but escalating to proactive legal efforts. The laws concerning accessibility are just as enforceable as those about exposure to tobacco or asbestos. There will be legal services to help in assuring that all of us can use the Web to its full potential.

In that vein is a recent case, the National Federation of the Blind vs. Target stores. Although it was settled out of court for millions of dollars (therefore not becoming “case law”), it has put the fear of huge lost revenue into many corporate entities that are now scurrying to attain accessibility and avoid such disastrous outcomes.

The nearly $10 million Target spent on attorneys would have been avoided had it spent a few tens of thousands of dollars on designing within the required specifications. “Programmers Now” is way cheaper than “Lawyers Later.”

If you include accessibility from the start rather than trying to “bolt it on” after doing the other chores of building a site, you will reap many benefits. There are documents at the WAI site making the business case for accessible design.

It’s up to us to insist on an accessible Web, starting right now. The tools for this are already in the hands of any competent professional Web designer, and the recourses are now well established in regulations. Dozens of countries have laws requiring compliance with WCAG, and there is even a U.N. decree concerning it.

If you’re familiar with coding html/css/javascript, go to <http://www.w3.org/wai> and look at the dozens of applicable documents, or get a good book such as “Universal Design for Web Applications” by Wendy Chisholm and Matt May, two of the many technologists responsible for the standard.

If, on the other hand the preceding paragraph makes little sense to you, then you are the really important part of enforcing accessibility rules. Just remember the acronym POUR represents the principles on which the guidelines are based, and whenever you have trouble with a site, see if it violates one of those basic principles.

Other technical links include http://www.w3.org/wai, http://www.w3.org/WAI/bcase and http://www.w3.org/WAI/participation.html.

William Loughborough is a frequent contributor to Independence Today. He has been involved in the Web Accessibility Initiative since its inception and has 50 years’ experience in providing devices for blind orientation.

Mona Golub, left, receives the Beacon Leadership Award on behalf of the Golub family from Sean Turley, president of the board of ILCHV, at the 15th Annual Dessert Spectacular fundraiser. Denise A. Figueroa, executive director of the organization looks on (right). DJ Richard Tollner in the background with the microphone. It was the annual fundraiser for the 22 year old center. (Photo property of ILCHV)