Linda Gonzales
Helping Rural CILs Drives Her

INTELLECTUAL DISABILITY COMMUNITY ENJOYING ‘BUS’ MEMOIR’S JOURNEY

COMMENTARY: ‘SILVER LININGS PLAYBOOK’ IS A REALISTIC PORTRAYAL OF MENTAL ILLNESS

MICROSOFT SPEECH RECOGNITION PROGRAM IS GREAT

BLIND GIRL IS WRITING HER OWN SUCCESS STORY

NEW U.S. DEAF BLIND PROGRAM MAKES GOOD CONNECTION

As with most children her age, Sofia is challenged academically, physically and socially. Academically, she is a top student; physically, she can keep up with her peers on the playground; and socially, she has friends inside and outside of school.

Sofia, a fourth-grader at Ledyard Center School, is challenged daily by an obstacle that all but one of her friends confronts. With a visual acuity of 20/500, she is legally blind. When asked how long she has been blind, she said, "I think my whole life, but we first knew it when I was 3 or 4."

Sofia has Leber’s congenital amourosis, a degenerative condition that leads to complete blindness. After years of medical visits and research, the gene that caused her blindness was identified.

Sofia can see small items up to six inches away, and she can distinguish details, and sometimes colors. Although her color vision is deteriorating, recognizing contrast has become increasingly important. Beyond that, the best she can see are shapes and shadows. Sofia is extremely sensitive to light and will sometimes keep her eyes almost closed. She usually wears sunglasses, even indoors.

Shortly after she was diagnosed as being legally blind, she started learning Braille. By 5, she was reading Braille, and now, she can read Grade 2 Braille. "I learned uncontracted Braille first, and now I know all of the contractions," she said. "I read and write in contracted Braille now. I don’t use uncontracted Braille anymore unless I have to."

According to the American Foundation for the Blind, Braille is a series of raised dots that can be read with the fingers. Teachers, parents and others who are not visually impaired ordinarily read Braille with their eyes. Braille is not a language; rather, it is a code by which languages such as English or Spanish may be written and read. Any combination of one to six dots may be raised within each cell, and the number and position of the raised dots within a cell conveys to the reader the letter, word, number or symbol the cell represents. There are 64 possible combinations of raised dots within a single cell. Due to the varying needs of Braille readers, there are three dif

Disability Publications Need Broader View

If you live with a disability, no one needs to tell you how often you are defined by that disability. You know too that there are times when what you can or can’t do in life is dictated to you by others simply because you have a disability and, in the eyes of still too many, you are your disability -- and nothing more.

Sometimes we are even named after our disability! I live with a brain injury as a result of being held up and shot in the head so, for some, I am a TBI (traumatic brain injury), not a human being -- certainly not a complete human being.

The completeness of one’s humanity is not determined or defined by disability any more than it is defined by eye color. Yet, still, this is all too often the way it is.

There are quite a few disability publications online and off. When I read them, I’m struck by a pattern that disturbs me: With rare exception, the entire content is about and only about disability. As a result, disability publications unwittingly foster and reinforce the perception that we hold no sway beyond the realm of disability. Nothing could be further from the truth.

Although disability publications need to shine a light on disability-related issues, they don’t need to, and should not, do so to the exclusion of everything else. Consider this: The disability rights movement is about our right to equality, to justice, to being seen and experienced as the complete human beings we are by the nondisabled and, not incidentally, each other. What better way to further this cause than by encouraging disability publications to include content that has nothing to do with disability -- pieces on politics, fashion, sports, economics, civil rights, law enforcement, humor, health care, entertainment, books, music, theater, education, animals, agriculture, you name it, or features on people, places and things that have zip to do with disability? The fact that many of these pieces will be written by people with disabilities and are in a disability publication will slowly but surely sink into the social consciousness and, by doing so, do more for the disability rights movement than many can imagine.

Think about it: When you read pieces in a newspaper or magazine or on the Web, if they’re any good, you are absorbed by the content, not whether the writer does or doesn’t live with a disability. Remember what Dr.
Helping Rural CILs Drives Her

By Janine Bertram Kemp

She's a braniac with gorgeous blonde hair and deep red lipstick. In these, her middle-age years, she still can turn heads. She is well dressed and moves through the world in her power chair. Linda Gonzales is also soft-spoken -- more of a doer than a self-promoter.

Gonzales is a leader who likes to anticipate issues. She sees problems coming and offers answers. She has been looking at the potential funding crisis for centers for independent living (CILs) and is primed to find solutions. She writes a blog for the Independent Living Research Utilization New Community Opportunities Center in Houston, Texas, that focuses on CILs. If your CIL wants to shore up its funding base because of recent or impending budget cuts, she’s got the time and inclination to help you execute workable plans that focus on local resources and community foundations as well as more traditional state and federal opportunities.

In national disability rights history, Gonzales is to rural independent living what Ed Roberts was to urban independent living: its founder. As director of the Association of Programs for Independent Living (APRIL), she got the organization on a firm footing and was the driving force behind its reputation as an innovator.

Gonzales became involved in the disability rights movement as a consequence of graduate school. She graduated in 1981 with a master of arts in education, educational psychology, and guidance counseling from California State University at Northridge, Calif. She had been working on her thesis on the psychosocial needs of people with muscular dystrophy at the same time as her own MD was worsening.

“For many years, I had a diagnosis and a hidden disability,” she said. “The last twenty years, it moved to the lower part of my body, and I eventually ended up using a reclining power chair.” In order to conduct research for her thesis, she attended the Muscular Dystrophy Association’s summer camps. She could have attended as a camper or an assistant.

“I met some wonderful people at MDA camp, including a gal who worked at Westside CIL in Los Angeles. She talked about the philosophy of IL, and it was similar to my conclusions. It was 1980, and I felt like I was building independent living all on my own. She said there was a movement that exists. I got my degree and became a peer counselor at WCIL. June Kailes was my first boss.”

Gonzales moved to New Mexico in 1982 as the New Vistas CIL in Santa Fe was being formed and remained there until 1993. In 1987, she married her husband, Jerry. Gonzales began work as an outreach worker, driving her van across the nine easternmost counties in the state. Crisscrossing the rural areas in that section of New Mexico, she got a feel for the values and the cultural and religious issues that affected the people with disabilities who lived there.

She eventually became a counselor and then executive director at New Vistas CIL. In 1986, ILRU began looking at how rural CILs were doing and, with funds secured from a grant, brought together directors from 12 states
Product Testing

Spread the Word: MS Speech Recognition Program is Great
By John M. Williams

Three years ago, I started having trouble typing. For decades, I averaged 45 words per minutes. Rather suddenly, my typing speed was fewer than eight words per minute. My daughter, Faith, commented: “Dad, you used to type so fast. What happened?”

As a writer, typing eight words per minute is a disaster. I had to find an alternative method to write articles, emails and other tasks.

Gradually, my left hand, as well as my left wrist, started to feel stiff. In addition, I started walking with a limp on my left side. I went to see a doctor and, after many tests and a five-day hospital stay, I was diagnosed as having early onset Parkinson’s disease. I was not sure how to cope with Parkinson’s, and I believed that my quality of life was in jeopardy.

Of one thing, I was certain: that assistive technology would play a major role in any therapy program that I entered. To increase my typing output, I started seriously looking at speech recognition programs. I had used speech recognition programs in the past over many years. I was never satisfied with the results. I toyed with some of them, but I never reached a degree of accuracy and productivity that I wanted. I wanted to use speech recognition mainly for word processing with the ultimate goal of using it to control my environment -- that is, turning my appliances on and off, making telephone calls, controlling the thermostat, and so forth.

I decided that, rather than buying a speech recognition program, I would use the speech recognition program

Intellectual Disability Community
Enjoying ‘Bus’ Memoir’s Journey
By Kathi Wolfe

When you write a memoir, you hope it will receive good reviews, sell reasonably well (in a TV- and video-oriented world) and touch some readers. You don’t expect your work to become not only a TV movie, but a phenomenon beloved by a civil rights movement.

Yet that’s what happened when “Riding the Bus with My Sister” by Rachel Simon came out 10 years ago. The memoir is about Simon’s evolving relationship with her sister Beth, who has an intellectual disability. A 10th anniversary edition of the book, with new essays by Simon and Beth, along with an essay on the changing intellectual disabilities community, was published this spring by Grand Central Publishing.

Simon tells the story of the year she rode buses with Beth. Some of the bus drivers form a supportive community for Beth. Beth is kind to them – sending them birthday cards and playing with their children. Simon draws you into her journey – from learning about public transportation to reconciling with her mother to understanding that people with intellectual disabilities have, like everyone, the right to self-determination. Simon’s private story of struggling to understand her sister and the concept of self-determination became public when the civil rights movement of people with intellectual disabilities was emerging. (To protect their privacy, Simon changed the names of everyone in her memoir except for herself and Beth. And the Pennsylvania city where Beth lives isn’t named.)

Simon recently conducted a wide-ranging telephone conversation with Independence Today that touched on what it’s like to be a sibling of someone with an intellectual disability to how she and Beth felt about the movie adaptation of “Riding the Bus.” Excerpts of the interview are as follows:
We all know Helen Keller’s story – or at least part of it. Born in 1880, she lost both sight and hearing at the age of 2. Isolated and wild, she was given the gift of communication – and thus the key that would launch her as a world-renowned speaker, writer and fierce defender of social justice – by a young woman, legally blind herself, named Anne Sullivan. For Helen Keller, the connection was made initially through the manual alphabet, finger spelling, and later through literacy as she learned to read and write Braille.

Today, there are an estimated one million Americans whose combined loss of sight and hearing places them in the category of deaf-blindness, and a relatively new piece of legislation now offers a similar promise of flinging wide the gates of connection to the world.

Part of the 21st Century Communications and Video Accessibility Act is the National Deaf-Blind Equipment Distribution Program (NDBEDP) designed to bring deaf-blind Americans into the world of telecommunications and thus within reach of the opportunity to participate in work, school and the wider social community.

Administered by the Federal Communications Commission, the NDBEDP has allocated $10 million each year for its two- to three-year pilot project to be used in all states to purchase equipment and training for qualifying individuals. While a contracting agency or organization has been selected in each state to process applications, select equipment and provide necessary training, many of those states are looking to the Perkins School for the Blind in Massachusetts and the Helen Keller National Center in New York to get a better feel for managing the details.

What kinds of equipment will the project provide?

Some people who are deaf-blind are completely deaf and completely blind. Some have some usable vision, others have some usable hearing, and most have their own unique blend of the two sensory disabilities. Consequently, the types of equipment that will connect an individual to communication vary considerably.

Essentially, any technology or telecommunications equipment that provides some link to communication and connection to the wider world is likely to be within the parameters of the NDBEDP. Specially designed products such as signalers that flash or vibrate to indicate the ringing of a telephone, for example, or Braille notetakers that connect to the Internet, or refreshable Braille displays that connect to computers for email and Internet access are being considered for the program.

Similarly, laptops and computers, oversized computer monitors that enable a person with extremely low vision to see content from the Internet or email messages, or text-to-speech software that reads aloud what is on the screen are all being evaluated. Also on the list are a variety of mobile devices such as iPhones, iPads, or other smartphones and PDAs that render communication and connection possible and offer accessibility features to individuals who have limited sight and hearing.

Who is eligible?

First, of course, the application process requires documentation from a physician or other health care professional that an applicant has sufficient loss of both sight and hearing to qualify as deaf-blind. Second, applicants must have proof of income that places them at or below 400 percent of the U.S. poverty guidelines. Specifically, in the continental U.S., an individual with an annual income at or below $44,680, or a family of four with an income at or below $92,200, is eligible. In Alaska, the threshold is $51,440 for an individual or $106,040 for a family of four. In Hawaii, both an individual with an income up to $55,880 or a family of four that earns $115,280 are eligible.

Perkins and the Helen Keller National Center have launched a campaign called iCanConnect in an attempt to spread the word and answer basic questions regarding the program.

Steven Rothstein, president of Perkins, believes that the promise of this legislation cannot be overstated. Currently, the FCC is still making the rules and figuring out the best direction to take the program.

“When you take the long view,” Rothstein said, “I believe the program has the potential to make more of a difference for deaf-blind individuals than anything that has happened since Helen Keller was enrolled at our school.”

Advocates say that the greatest challenge, given the nature of the double disability status of deafness and blindness, might be locating the people who need and will reap the greatest benefit from the program.

To locate the contact organization in your particular state or to download a brochure about the program guidelines, visit iCanConnect.org.

Deborah Kendrick is a writer and editor. She is currently working on a biography of Dr. Abraham Nemeth.
Sophia

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different grades of Braille.

In Grade 1, each possible arrangement of dots within a cell represents only one letter, number, punctuation sign or special composition sign -- it is a one-to-one conversion. Individual cells cannot represent words or abbreviations in this grade of Braille. Because words, books and other documents cannot be shortened or abbreviated, Grade 1 Braille is bulkier than other grades and requires larger-than-normal printed text. Grade 1 Braille typically is used only by those who are new to the system. As of the early 2000s, some elementary school teachers began introducing Grade 2 Braille to children with sight difficulties immediately after they had learned the basics of Grade 1 Braille.

Grade 3 Braille is essentially a system of Braille shorthand. Because it has not been standardized, it is not used in publications. Instead, it is typically used by individuals for their own convenience. It contains more than 300 word contractions and makes great use of vowel omission. In addition, the amount of spacing between words and paragraphs is decreased in order to shorten the length of a document. Sometimes, it substitutes combinations of punctuation symbols for words.

Sofia uses a variety of assistive technology products at school and home, including JAWS (Jobs Access with JAWS is a screen reader developed for computer users whose vision loss prevents them from seeing screen content. It reads aloud what's on the computer screen.

A BrailleNote is a computer made for persons with visual impairments. It has a Braille keyboard, a speech synthesizer, and a 32- or 18-column refreshable (electronic) Braille display, depending on the model.

Sofia uses assistive technology to take notes in school and then send the assignments wirelessly to an embosser to print in Braille and to a teacher’s personal computer for printing and correction.

A CCTV (closed circuit television) system, or video magnifier, provides low-vision aid for a full range of visual needs, such as macular degeneration, glaucoma, cataracts, retinitis pigmentosa and diabetic retinopathy. A CCTV magnifier can help users read mail and books, write, tackle a crossword puzzle, connect to a computer and much more. Sofia uses the CCTV for reading, assembling puzzles and playing with Legos.

The iPad’s magnification feature helps Sofia see the board.

“T use all of my technology,” she said. “I use the iPad so I can see the board in school.”

She can synch the iPad’s content to a Promethean board or Smart Board. A Promethean board is an interactive learning whiteboard that connects to a computer. This technology allows Sofia to have hands-on practice and personal involvement with learning. Smart Boards meld high-tech functionality and tradition by acting as a computer monitor and a chalkboard at the same time. Smart Boards instructors can show videos, write equations and check homework all on the same board in the classroom.

“I usually use the CCTV to read or see the white board, which we don't use as much,” Sofia said.

Sofia can download books from bookshare.org to her BrailleNote, with which, she said, “I can read and play games with it.”

She mainly uses BrailleNote to write documents or stories for the school’s Writers Club. Her life’s goal is to be a writer, she said. “I have a lot of stories to write.”

“She’s extremely driven and competitive, not to mention fiercely independent,” said her mother, Laura. “Her independence has served her well so far. I have no doubt it will always serve her well.”

John Williams coined the phrase assistive technology. His e-mail address is jwilliams@atechnews.com.

Broader View

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Martin Luther King Jr. said about being judged by the content of our character, not the color of our skin. The same tenet holds here. We deserve to be judged by the content of our character, the content of our publications, not whether the people behind the publication live or don’t live with a disability.

All newborns, disabled or not, enter this world deserving equal rights. There are no exceptions. Those of us active in the disability rights movement must draw attention to any and all who seek to deny, restrict or impede those rights. But we must also make every effort to help our nondisabled brothers and sisters discover our just claim to these rights. We must be creative and self-aware. We must check and double-check to make sure our choices
One night in 1985, I am watching a movie called “The Theresa Saldana Story,” the story of an actress who was stalked and stabbed repeatedly by her stalker. To my amazement, she playsedly by her stalker. To my amazement, she playsedly by her stalker. I am glad I am alone and freezing cold. Soon, I am trembling uncontrollably. I feel a bit queasy, nauseous. I am beginning to sweat. I excuse myself from the table.

Suddenly, I don’t feel good. I’ve had a sip or two of coffee, and now I feel a bit queasy, nauseous. I am beginning to sweat. I excuse myself from the table. By the time I enter the men’s room, I am pouring sweat and freezing cold. Soon, I am trembling uncontrollably. I am glad I am alone.

The trembling is getting worse, my stomach is cramping, and I am now doubled over. I go into one of the stalls, sit down on the toilet, and lean my head against the cool stall wall. The coolness is comforting. I try to stand, but the trembling and cramping are too much. I see drops of sweat dripping off my face onto the floor. My shirt is soaked through.

And I can’t stand up! I am still doubled over and out of breath and wonder if this is some kind of a seizure. Is this what a seizure’s like? I am in trouble, and I know it. I need to get help.

I hear someone come into the bathroom. I have to stand and get out of the stall and ask for help. I hear water running as I get to my feet. Still doubled over, I get the stall door open and, to my great relief, see that the man who has come into the bathroom is a member of the Philadelphia VFV board. He is at the sink, splashing cold water on his face. I make my way over to him. I place my left hand on the counter, then reach out and touch his shoulder with my right hand.

“Excuse me,” I begin.

Then, in a truth-is-stranger-than-fiction moment, he says: “One moment, please. I’m an epileptic, and think I may be about to have a seizure.”

“Take it easy, bro,” I say. “You’ll be OK.”

In a moment, his concern passes, and he turns to me. “Jesus, you OK?”

“Something’s really wrong, bro. Please get me some help.”

The bathroom is soon crowded with people from VFV. Maria is dabbing sweat off my face with a towel.

“The ambulance’s on the way, Peter,” she says. “Everything will be all right.”

“I’m so sorry, Maria.”

“It’s OK, Peter. We all love you. Just try and relax.”

Soon, two paramedics arrive. One of the paramedics kneels down next to me. I guess him to be in his early thirties. The other paramedic is older, maybe early fifties, with brown hair. Both are very kind and attentive. The younger one speaks.

“What’s your name?” he asks.

“Peter.”

“How you feeling?”

“Crappy. How about you?”

He laughs. “Better than you, but we’ll take good care of you.”

“You bet,” the older one says as he wraps a blood pressure cuff around my arm.

The younger one says, “What do you think’s wrong, Pete?”

“One-ninety over 100,” the older one says.

“I don’t know if it’s a seizure or the bullet’s acting up,” I say.

“What bullet?”

I tell him. The paramedics become even more compassionate and concerned. I ask: “Do you think it’s a seizure? Should there be something in my mouth to keep me from swallowing my tongue?”

“Old wives’ tale,” the young one says.

“What if I swallow my tongue?”

“I’ll take it back out for you.”

“I appreciate that.”

“Thought you might.”

Once I am in the hospital emergency room, I begin to feel better. The doctor tells me what’s wrong: “It was a big-time anxiety attack, Pete. A panic attack.” He has a curious look on his face.

“You’ve never gone through one before?”

“No, that’s my first.”

“Pretty remarkable given what you’ve been through.”

"Panic Sets In -- and Help Turns Out"

By Peter S. Kahrmann

INDEPENDENCE TODAY

Panic

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for a three-day meeting in Houston.

“Twelve of us got together and fell in love with each other,” Gonzales said. “Each of us had been feeling like we were the only ones. We found out that so many of the things we experienced were similar: mileage reimbursement checks larger than our paychecks, huge catchment areas (the CIL-eligible population in that region), lower funding, isolation.”

In discussions, the group concentrated on NCIL because of its national profile. Although the National Council on Independent Living had a rural subcommittee, its orientation was mostly urban. APRIL was born out of the idea that it would be helpful to have an organization that focused on rural issues.

“In the late 1980s, we started meeting, and some were held at the NCIL conference,” Gonzales said. “Word grew that we were factioning the movement, starting a different organization, that we were not really CILs. Things were pretty tense for a time.”

Social documentarian Tom Olin, who worked with Gonzales on APRIL’s youth mentoring project, recalled the organization’s controversial beginnings. “For a time, there was discord between NCIL and APRIL,” Olin said. “Linda Gonzales never fed those fires of division. She kept APRIL running for a long time with very little money, and that is not the easiest thing to do.”

Tom Seekins, director of the Research and Training Center on Disability in Rural Communities at the University of Montana, has been a colleague of Gonzales since 1993.

“When the Rural Institute was funded, Gonzales came and advocated that our center address independent living issues,” he said. “It was originally intended to address medical, rehabilitative and assistive technology. It took an advocacy effort to change that. We had to work through it, and we did.

“Linda made a significant contribution to the disability rights movement when she took a gamble on rural independent living,” Seekins continued. “She had a secure position as director at the Santa Fe CIL. She was doing great things, but for some reason she saw the need for a focal point on rural disability issues and took on the responsibility to be that organizing force for APRIL. Linda took that risk with no funding and not many resources except the trust and commitment of other CIL directors around the country.”

Gonzales tells the same story with a slightly different twist. “At about the same time we organized, the University of Montana got funding for the Rural Institute on disability. At APRIL, we said, ‘They can’t be talking about these issues without having us involved.’ We struggled for a few years. Then the Department of Education gave us a five-year demonstration project to implement a transportation voucher system, and that allowed us to build the infrastructure and hire staff.”

With the grant, which came in 2001, Gonzales focused on transportation. “It was a huge stumbling block for everyone out there in rural areas,” Gonzales said.

During the George W. Bush presidency, APRIL led the struggle that convinced the Federal Transit Administration that transportation vouchers were a legitimate use for New Freedom Initiative funds and should be specified in regulations.

“I admired her so much,” Seekins said. “APRIL was a small organization, struggling to survive. She held it together and led the organization to the point (that) it became vibrant.”

More than 15 years after Gonzales launched APRIL, she is entering a new phase of life. She writes a blog for ILRU and is on the Consumer Advisory Board for the Center for Research on Women with Disabilities (CROWD) at Baylor College in Houston, founded by colleague Margaret Nosek.

“Linda and I go way, way back,” Nosek said. “I first met her when she was director of New Vista CIL in Santa Fe. Much later, we discovered we both grew up in Cleveland and our mothers dragged both of us to an MDA clinic at University Hospital.

“Linda’s impact is interpersonal,” she continued. “She is a dynamic individual but subtle. Linda relates to people with disabilities on a personal level. She can bring rural issues and independent living from the personal to the political. She can go from the individual and turn it into valuable information and opportunities for people to come together and work.

“Her best vehicle was as director of APRIL. That gave her both a platform and vehicle to affect many lives. She doesn’t let anything stop her. For some whacko reason, she has landed in Colorado where, because of the altitude, she has to use oxygen. Yet she still continues her work. She is still bringing all that same energy, expertise and ca-

Gonzales
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Gonzales
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Q: Originally, you wrote a newspaper article about riding the buses with Beth. What gave you the idea to do a book about it?

A: After the article came out, people said, “You should write a book about this.” But I was totally opposed to it. My sister jumps around from bus to bus. I couldn’t figure out the structure. We weren’t getting along. It wouldn’t have been flattering to me, and I hadn’t come to terms with her bus riding. When she asked me to go bus riding with her, I wasn’t planning to write a book.

But the bus drivers were ... interesting. She (Beth) picked good ones to ride with; they’d been through the “school of hard knocks.” I’d studied anthropology. With the drivers telling their stories, I started thinking like an anthropologist. I started tape-recording their stories. After a few months, I thought maybe I should write a book. I put together a proposal focused on the bus drivers. Beth and I would be incidental.

It got to be Thanksgiving weekend. I told Beth I hated her because she didn’t want me to borrow a towel. She was hurt. I felt terrible. I said to a friend: “I’ve got to tell the publisher I can’t write the book. I just told my sister that I hate her.” My friend said: “That’s why you have to write the book. It’s about the truth – a relationship between two real sisters. That’s why the book will matter.”

I realized my friend was right. What was important about the story was my coming to a level of awareness about Beth living a life of her own – about her having the right to make her own choices.

Q: From riding the buses with Beth, you embraced the idea of self-determination. Yet, you feel that this is a complicated concept. Why is this civil rights mantra for people with intellectual disabilities so complex?

A: Self-determination can be a sticky wicket. My sister’s life is one big manifestation of self-determination. I haven’t met any family member who hasn’t found self-determination to be complex. I learned that we’re in a new time. If Beth doesn’t want to take her medications, she doesn’t have to.

To show your love for somebody, you want to make them be safe. You think you’re making things safe for them, but you’re trying to make them conform to your image of who they are. It’s not the ideal way of interacting with someone if they feel they’re going to be judged. I spoke once at a local ARC. I remember a young man was there. He said I should tell Beth to stop riding the buses and get a job, and he gets services from the ARC.

People ask me why Beth doesn’t come with me when I give my talks. I say because she’s doing what she wants to be doing (riding the buses – living her life). It’s challenging. Self-determination is a work in progress.

Q: Writing and talking about “Riding the Bus” helped you to become connected to the community of siblings of people with disabilities. What have you learned about being a “sib”?

A: One thing I learned as a typical “sib” was that we’re kept out of the information loop. The parents wonder, How do I handle the “typical” kid (the child without a disability)? Do I bring the typical child when I take the child with a disability to the doctor’s or the IEP (individualized education plan) meeting? My parents determined not to. What does the sibling want? It keeps changing during your

Rachel Simon, right, and her sister Beth.
provided by Microsoft Windows 2010. You will find the program in the control panel section.

In June 2012, I started using Microsoft’s speech recognition program. I was not expecting much. I was as wrong as people who once believed the world was flat. In a little more than an hour, I was writing my first article. About two hours after I started using speech recognition, I had a 1,000-word draft completed, which included corrections. I was pleased. I was stunned. I was surprised. It seemed too easy.

Microsoft’s simple, five-step program to learning speech recognition is as follows:

1. Start your speech recognition program.
2. Set up your microphones.
3. Take the speech tutorial.
4. Train your computer to better understand you.
5. Open the speech reference program.

None of these activities take long to complete. They build on each other. I recommend completing all five activities before starting speech recognition.

Steps 3 through 5 are critical if you want to master speech recognition. The third step teaches you to use your computer with speech, the fourth step is a good training exercise for your computer to get to know your voice, and the fifth step is a list of commands to keep with you so you know what to say.

In a short time, I learned to write paragraphs, scroll up and down, open windows, close and minimize windows, and switch between running programs. One of the easiest tasks to master is inserting punctuation and special characters. Another is common speech recognition commands.

I use speech recognition for all my writing activities. To write with the program, I speak three or four words. Ninety percent of the time, speech recognition is correct. Sometimes, though, the program has trouble distinguishing among words such as “for” and “four”; “then” and “than”; “two”, “too” and “to”; “roll” and “row”; “night” and “knight”; and “site” and “sight.” Many times when I stutter pronouncing a word, the word that appears is wrong. Correcting the word is easy. I say “de-le-te” and then say the word I want.

When using speech recognition, I wear headphones to drown out competing noises. Such noises can produce the wrong word, punctuation or symbol or nothing at all.

When I was growing up, I had a friend who shared my disability of blindness. Like me, she loved to read. One Christmas, Gayle’s parents bought her a book, and I marveled at and was envious of her good fortune.

The book Gayle received was “Pinocchio” in Braille. It was two large volumes, each the size of a metropolitan telephone book. I don’t know if it was her favorite story. It wasn’t mine. But I knew she really loved me when she let me borrow it for a week.

For children who loved to read and whose only accessible reading medium was Braille, any book was a rare treasure. In our resource classroom at school, there was a small “library” comprised of two shelves in the back corner. I read every one of the books there, in some cases several times. The addition then, of talking books — records that featured professional narrators — was especially welcome.

In the 1960s and 1970s, with faster Braille embossers and the advent of cassette tapes, the availability of books for blind people increased dramatically. Nothing, however, revolutionized the availability of books like the personal computer and the plethora of products that began appearing in the specialized market of products for blind people in the mid-1980s.

With personal computers that could magnify text on the screen, read every word aloud via a speech synthesizer, or display all information in Braille on refreshable displays, the world of information exploded before the eyes, ears and fingertips of people with limited or no eyesight. In 1999, when the National Library Service for the Blind and Physically Handicapped (NLS) launched its Braille website, Web-Braille, access to books took another giant leap forward. Now it made titles that had been produced in Braille available for download to personal notetakers and desktop computers outfitted with Braille displays.

At about the same time, a corporate entity called Audible.com was launched that targeted the 93 million Americans who commute to and from work each day. Audio books on cassettes and compact discs had, by this time, been making their way into the commercial market, so it was not uncommon to find newly released titles in both audio and print arriving on bookstore shelves on the same day. (This was one example of blind people actually being ahead of the curve, be-
Realistic Portrayal of Mental Illness a Credit to ‘Silver Linings Playbook’
By Kathi Wolfe

When I was growing up in South Jersey, we shied away from or whispered about people with mental illness, but we talked at the top of our lungs about the victories and defeats of our adopted team, the Philadelphia Eagles. Even now when I go back home, I root for the Eagles to win as if the fate of the earth depended on it, though I wouldn’t know a pigskin if I fell on it.

I thought of this when I saw “Silver Linings Playbook,” a star-packed movie just out on DVD that features Philadelphia, the Eagles, dancing, romance and characters with mental illness. The film, adapted from the novel of the same name by Matthew Quick, is directed by David O. Russell.

In my youth, most people with mental health impairments hid their disability. Thankfully, in “Silver Linings,” Pat, a high school history teacher who is bipolar (Bradley Cooper), and Tiffany, a widow with a psychiatric disorder (Jennifer Lawrence), live their lives openly. In the movie, mental illness doesn’t define the characters: It’s treated as an important, but not the only, facet of their lives. Pat and Jennifer, like people with and without mental illness, fight, eat breakfast, dance, watch football and fall in love. Though they struggle with medications, therapy and anger management, they’re well-rounded human beings, not one-dimensional stereotypes.

This is far different from the way in which people with mental illness have historically been depicted in most movies — even today. In general, when it comes to psychiatric disabilities, it’s been “crazy town” in Tinseltown. Take “The Snake Pit,” the 1948 drama that features Olivia de Haviland in a straitjacket in an infernolike “insane asylum.” Or “One Flew Over the Cuckoo’s Nest,” the 1975 Oscar-winning film with Jack Nicholson as “Mac.”

Closing old state institutions where hordes of people with disabilities live has become the norm in the 21st century. But Illinois Governor Pat Quinn’s attempt to methodically phase out his state’s “developmental centers,” as they are called, has met with fierce opposition from the union representing employees of the centers and from family members of some residents.

The rhetoric of the opposition is based on casting doubt on the ability of residents to function in smaller community settings. So disability organizations pushing to close all of the state’s seven remaining institutions are fighting back with an information campaign called Going Home Illinois (goinghomeillinois.org) that spotlights former institution residents and their family members who are opposed to institutionalization.

In 2011, Quinn, a Democrat, announced his “rebalancing initiative,” which called for the closure of four state institutions over 30 months. The first to go was the 160-year-old Jacksonville Developmental Center (JDC) in downstate Jacksonville. Residents were to be individually transferred and placed in smaller community-based settings whenever possible using person-centered planning.

Council 31 of the American Federation of State, County and Municipal Employees howled against the initiative from the start and has continued to organize protest rallies. Council 31 public policy director Anne Irving said the initiative was “endangering the lives of many of the severely disabled individuals who live at JDC by rapidly and irresponsibly forcing them to move into inappropriate settings that cannot meet their needs.” A link to a video from SaveJDC.com appears on the Council 31 website and features families of JDC residents at the time pleading to keep the place open while sad piano and cello music plays in the background.

But Quinn would not be deterred, and the JDC is now closed. Next on the list is the Murray Developmental
The hotel is called, and Maria comes to pick me up. She gives me a hug and asks if I want to go to my room when we get back to the hotel.

“No, let’s go back to the meeting.”

She is surprised. “You want to go back to the meeting? They are all worried about you.”

“Absolutely. There’s victims in that room just like me. They see me come back, maybe it helps them down the road.”

When I walk back into the meeting, there is applause. I am humbled, glad to be alive and ask for a cup of coffee.

Peter Kahrmann is a writer and an advocate for people with disabilities.

*Memoir Continued from page 9*

life. The way I felt about Beth when I was riding the buses is different from what I feel now. I’ve given talks to the parents about the sibling experience. The adult sibs in the room tell me they could have finished my talk for me.

Q: A television Hallmark Hall of Fame adaptation of “Riding the Bus with My Sister,” starring Rosie O’Donnell as Beth, and Andie MacDowell as yourself, was made in 2005. How did you and Beth feel about the movie?

A: I’m glad the movie’s there. A lot of people who can’t read or won’t read (the book) can know the story. If you’re readers, you’ll get more out of the book. There’s more depth. The producers, writers and Rosie met with me. They let me review the script. I knew the movie would be different (from the book). For instance, in the film, Beth is quick to anger. This isn’t true in real life. Rosie added some physical quirks to Beth that were a complete in-vention. Beth wasn’t upset. We asked Beth how she felt about Rosie’s portrayal of her. She said: “She’s not me. I’m still one of a kind.”

Q: Do you worry about how federal and state budget cuts (especially the sequester) will affect people with intellectual disabilities?

A: Only about 28 hours a day! I try not to be political, but it ultimately ties into politics. I’ve never been able to cast a vote without thinking. What has this candidate done to make my sister’s life better or at least not worse? If you’re not going to support this large segment of society that society ignores, I don’t want to know you. You’re the kids in the junior high hallway who are snickering, and the heck with you.

Kathi Wolfe is a writer and poet. Her chapbook “Helen Takes the Stage: The Helen Keller Poems” was published by Pudding House.

*Gonzales Continued from page 8*

maraderie, and she is excited in her low-key way.”

CROWD has done extensive research on women with disabilities, and Nosek is looking forward to working with Gonzales on the group’s latest project: a weight management program for women with mobility impairments.

“(Gonzales) is tied into so many networks, and that will be really helpful for us as we set up a community of practice,” Nosek said.

In the early part of this decade, the Gonzaleses got caught in the early stages of the housing crisis bubble and left Ohio in a motor home they called Grace. They had expected to have funds from selling their Ohio home and figured that Grace would be the vehicle in which to sample different areas until they found a spot to settle down in their retirement dream home. But the recession left them without that nest egg.

In a speech called “Lessons Learned Living in Grace” that she gave on the occasion of receiving APRIL’s Lifetime Achievement Award, Gonzales related how she and Jerry had a dream that didn’t pan out. Perhaps her work with CROWD to find solutions for CILs will be the conduit for making another dream come true.

Janine Bertram Kemp is a writer, advocate and president of the Disability Rights Center. She also is a member of ADAPT.

*Speech Continued from page 6*

When dictating, because I speak in phrases, I can produce 50 to 55 words per minute. Using speech recognition, my productivity has increased. So has my stamina.

In the morning, when I turn on my computer, a microphone icon appears on my home page. After putting on my headphones, I say, “Computer, open Google.” Then I am ready. In the evening, to turn off speech recognition, I say, “Stop listening.”

Speech recognition has made a major difference in my life. It can in yours. I recommend trying Microsoft’s speech recognition program. Being independent is important to me. Speech recognition keeps me independent. It can add to your independence.

What are you waiting for?

John Williams is a regular contributor to Independence Today.

*Broader View Continued from page 6*

are not, albeit unintentionally, supporting the view that we are about and only about disability.

Disability publications that make sure that their content consists of more than just disability-related subjects is a powerful step in the right direction. It’s inclusive. And inclusion is in so many ways a progeny of equal rights in the first place.

Peter Kahrmann writes a blog on disability issues. He resides in Massachusetts.
cause talking books produced for people with reading disabilities were available about 50 years before they made their way into the mainstream marketplace.)

The stroke of genius of Don Katz, Audible’s CEO, was to make audio books available via download. Rather than schlepping around tapes or discs, a customer could download a popular book or magazine to a computer and listen either on the computer or on a dedicated playback device. Today, Audible, which was sold to Amazon in 2008 for $300 million, has more than 100,000 titles.

Not surprisingly, many savvy book lovers who were blind were early adopters of the Audible model. Although prices were lower than in bookstores, Audible downloads were a decidedly commercial product, a luxury item to some, which limited their appeal.

Spurred by the success of Audible and Web-Braille, the NLS launched Braille and Audio Reading Download (BARD), its own talking book collection of downloadable digital audio files, in 2006. It became an instant success.

Two other significant players in this landscape of downloadable books were Bookshare, a project of Benetech Corp., and what is now called Learning Ally. The former, launched by Benetech CEO and MacArthur fellow Jim Fruchterman, was based on the Napster concept. Eligible participants (that is, individuals with print-related disabilities) upload the electronic files of books they have scanned with optical character recognition software for sharing with other Bookshare customers. The service now boasts more than 60,000 titles. Learning Ally, formerly Recordings for the Blind and Dyslexic, long established as the primary source of textbooks particu-
Center in downstate Centralia. Council 31 continues to protest, joined by some family members of Murray residents. Going Home Illinois seeks to give Quinn political cover by showing that the JDC closure was far from the cruel disaster some make it out to be.

Going Home is a coalition effort spearheaded by the Arc of Illinois. Tony Paulauski, Arc of Illinois executive director, said that developmental centers are like “the Edsels of the auto industry. There’s nothing innovative about the structure. It’s pure caretaking. This is the most restrictive setting. No one moves out. They’re just locked in there.”

But, Paulauski added, “Illinois has been in a stranglehold by the union. It’s all about jobs.” And the success of the union’s message, he said, relies on reinforcing stereotypes. “It all goes back to a lack of respect in how the public views people with disabilities. They’re a devalued property in most people’s eyes, so the priority has been how to change the system. We knew we had to put a face to the issue.”

There are many success stories resulting from the Jacksonville closing, and the purpose of Going Home is to make sure those stories are heard by lawmakers, the media and anyone who will listen.

Jennifer McCarrey, 34, is one such person. She lived in the JDC until last November. She spent about five years there after transferring out of another state institution that closed down. Now she lives with two other women in a group home discreetly nestled in a residential neighborhood on the north side of Chicago.

“I was kind of upset about (the JDC closing) because I was afraid some of my friends wouldn’t make it in group homes,” she said. “I knew that I had to go, move on with my life. It was too big. It had too many people. Too crowded.”

Would she go back? “Heck no. It’s not for me. I’ve moved on with my life. It’s a lot better than Jacksonville, I’ll tell you right now.”

In her new home, she has her own bathroom, which wasn’t the case at the JDC. She also enjoys helping prepare meals and plan menus. At the JDC, she said, you ate what you were given. “The food was precooked. We had to put it in the oven, and I didn’t like it too well.”

McCarrey said she has multiple disabilities. “I do have a big problem with hearing voices sometimes,” she said. She also has an intellectual disability. Twice before, she said, she tried community placement and ended up back in the institutions. She said she got so angry at a group home staff member that she assaulted her and was arrested.

“I learned from my mistake,” she said. So she thinks others who have tried and failed in the community deserve the right to keep trying. “I’d say, ‘try a house, like I did. It’s a lot more freedom. Try again until you do find the right house.’”

Five years from now, McCarrey hopes to have her own apartment and a job at a day care center for children.

Another component of Going Home is the Family Transition Project. Its purpose is to convince family members of residents of institutions that community-based options work and to offer them transitional support.

The project coordinator is Katherine Hamann. She is the guardian for her sister, Margaret Doering, who lived in Illinois state institutions from 1945 until Hamann transferred her to a group home in 2007.

Hamann said that Doering, who is 10 years her senior, was taken away to an institution when she was about 2 years old. She was vaguely diagnosed as “retarded,” said Hamann, who believes that Doering has some sort of autism.

Her parents kept Doering’s very existence a secret from her siblings when they were children. When Hamann first
met her sister as a teenager, she was living in a remote institution. “There was this giant day room,” Hamann said. “They took us to this locked area, and they unlocked this door to this giant hall.”

Doering eventually landed at an institution called Howe, which was closed in 2010. Hamann volunteered at Howe and eventually became a staff member, so she got an inside view.

“The more I observed of day-to-day life at Howe, the more I realized that even if Margaret was relatively safe, her quality of life was minimal. Meals came frozen on trays that were reheated in special ‘retherm’ units. Her home had a bus station atmosphere at the best of times. Margaret didn’t get many of the activities her program specified. There was very slow follow-up on medical issues.

“I knew that some people had bad experiences with community homes and in some cases had come back to Howe,” Hamann continued. “However, I also knew that some bad things happened at Howe.” So she wasn’t among those who fought to keep Howe open at all costs. Instead, she searched for a community-based option for her sister.

Today, Doering lives in a six-resident group home in suburban Chicago. “I will always worry about her,” Hamann said. “But I would never let her go back to an institution. She has a life now. She has become friends with another woman in the house. I don’t know that she’s ever had a friend before. Sometimes they sit and hold hands. If she wants some privacy, she goes to her room and rocks in her favorite chair. No one tells her she got an inside view.

In her current job, Hamann said she has talked to more than 100 family members and guardians, trying to convince them to insist on the best for their loved ones. “Families are used to getting second best because we’re afraid to rock the boat and get nothing or get something worse than what we have now.”

In April, Quinn addressed a spirited Going Home rally outside the Capitol in Springfield as people who had once been in state institutions were gathered nearby. Quinn said his rebalancing initiative will “last a long, long time and make history” in Illinois. “I believe the strongest force on earth is when thoughtful, committed people band together for a cause they believe in.”

Mike Ervin is a writer who lives in Chicago. His blog, "Smart Ass Cripple," appears at smartasscribble.blogspot.com.

Audio Books

Meanwhile, with the growing popularity of iPhones, iPads and other commercially available products accessible “out of the box,” providers of accessible books have quickly caught the wave. Audible’s books can be played on iOS and android devices. Learning Ally and Bookshare have apps for both platforms as well. And NLS will be releasing its app for both platforms before the end of the year.

A few months ago, HumanWare introduced a new and improved Victor Reader Stream. Smaller by a third with a louder internal speaker, the new Reader Stream plays all the popular content types (with the exception of Audible at this writing), has new features such as time announcement and alarm, and still makes recordings.

With this unimagined wealth in literature now available to people with reading disabilities, the main concern now is how best to listen to it. Because financial resources are not limitless for most people with disabilities, choosing just one product that best suits individual needs is not easy.

If making DAISY recordings is a priority, you will probably want a PlexTalk pocket. If having an FM radio and making recordings from it matters to you, a Book Sense would be your player of choice. If wireless accessibility is a must, the new Victor Reader Stream or PlexTalk will head the list. If your primary objective is to carry only one device wherever you go, you could pay for the Bookshare app (Read2go for iPhone, Go Read for androids) plus an Audible subscription and read books with your phone. If, however, you only want to listen to books available from the NLS BARD and don’t feel it necessary that your player fits in your pocket, you could keep your money in the bank and use the outstanding digital talking book player provided free of charge to all eligible patrons.

McMurphy, who’s an inmate in a prison farm for raping a 15-year-old girl. He thinks his life will be better if he’s transferred to a mental hospital. But little does he know that he’s going to meet infamous Nurse Ratched.

If your only knowledge of mental illness comes from movies like these, TV crime shows that feature “insane” killers, or news reports linking violence to psychiatric disorders, you’re likely to think that people with mental illnesses are violent or “crazy.” Yet, according to mental health experts and advocates, most of the one in four people who will have a mental illness in their lifetimes are no more violent or “cuckoo” than people without psychiatric disorders.

Though Pat and Tiffany are engaging, nonstereotypical characters, “Silver Linings” doesn’t sugarcoat what it’s like to have a mental illness or to live with someone with a psychiatric disorder. Pat’s bipolar disorder is triggered when he discovers that his wife, Nikki, is cavorting with a man in the shower. He’s forced to enter a mental health facility after he tries to beat up the guy. Nikki issues a restraining order against him.

The movie begins when Pat moves back in with his parents after being released from the hospital. Under the care of his mother and his father, Pat continues his treatment. We discover that this family goes nuts for the Eagles and that Pat Sr. (Robert de Niro) has obsessive-compulsive disorder. Along the way, Pat meets Tiffany. Spoiler alert: Pat Sr. is a bookie. Some of the best moments of the film occur when Pat Jr. and Tiffany trip the light fantastic at a dance competition and when Pat Sr. makes a hair-raising bet at an Eagles game.

As you may have guessed, the characters of “Silver Linings” aren’t brave, heroic or “inspirational.” Pat barges into his parents’ bedroom in the middle of the night, ranting loudly about an Ernest Hemingway novel. He’s incensed that Catherine, the heroine of “A Farewell to Arms,” dies. Tiffany cusses like there’s no tomorrow, yells a lot and is rude to her family. While Pat Jr. and Tiffany are interested in undergoing treatment for their mental illness, Pat Sr. seems to have no interest in seeking treatment for his OCD.

Yet, despite their cantankerousness, you like these characters. You know it’s a Hollywood movie, but the interactions and relationships seem real. In reel, as in real, life, some people with mental illnesses want treatment, and others do not. Though most of us don’t have OCD, which is a psychiatric disorder, or an addiction to gambling, many of us love a good bet and have our pregame rituals. If you wear a T-shirt with your team’s mascot on it during every game (as some of us do), raise your hand. Perhaps what makes “Silver Linings” feel authentic is that the film director’s son has bipolar disorder and that Quick, the author of the novel on which the movie is based, has had depression.

“Silver Linings” isn’t a documentary. It’s a dramedy – an entertaining mix of drama and romantic comedy. Still, I wish Pat’s Sr.’s OCD had been depicted more seriously in the movie. Watching this film, you could, if you were uninformed about OCD or a gambling addiction, come away thinking that these disorders don’t need treatment – that these problems can be solved with luck, rituals and family togetherness.

Despite this caveat, I recommend “Silver Linings Playbook.” It’s a great date night or buddy night flick that offers humor, sports, romance and a nuanced take on mental illness.

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Kathi Wolfe is a writer and poet. She was a 1998-1999 Rosalynn Carter Mental Health Journalism Fellow.