A PHYSICAL – AND MENTAL – STRUGGLE

FACEBOOK
A REAL FEEL-GOOD STORY

ADVOCATES RALLY TO CORRECT CIVIL RIGHTS OMISSION

NDRN EXECUTIVE DIRECTOR CURT DECKER

WRITER SUSAN NUSSBAUM BRINGS TO VIEW THE ‘HIDDEN’ WORLD OF DISABILITIES
Cassette or Digital Voice Recorder? One Journalist’s Recommendation

By John M. Williams

Recently, I was on a panel of writers talking about journalism before 20 high school seniors with disabilities who are interested in writing careers.

The students were interested in learning how to approach a story and in what kind of tools a journalist uses. Those tools, the students learned, include cameras, pens, tablets, cell phones and tape recorders. Sarah Jacobson spoke about the benefits of digital cameras. Tommy Mason addressed the benefits of cell phones.

One of the students, 17-year-old Carla Sanchez, asked me: “Mr. Williams, I noticed you have two handheld tape recorders with you. How valuable is a tape recorder to you? And is it a regular handheld recorder or a digital recorder? What is the difference between the two recorders? Should a person like myself who is legally blind use one?”

“Good questions,” I responded.

Before elaborating, I recalled conversations I had decades ago with two editors about the value of using tape recorders when interviewing. One of them said to me, “The shortest tape recorder on record is the human memory.” A second editor told me, “Protect yourself and, when possible, record all of your interviews.”

I took their advice and purchased a portable cassette player. It was cumbersome to carry. When handheld tape recorders came on the market, I purchased one. I was glad I did. When it wore out, I purchased a second one. About eight years ago, I purchased a third one for the final time. All three were Sony products; they operated similarly and looked the same. The first handheld tape recorder cost $99. The next two ran $79 each. In addition, I purchased six cassette tapes for $5 with each purchase.

Each side of the two-sided cassette tapes ran 45 minutes. In all the years I used a cassette tape recorder, I never...
Many roads brought Susan Nussbaum to the point at which she wrote her amazing novel Good Kings Bad Kings. She was attending theater school in Chicago with aspirations of a career as an actor and playwright when she was run over by a car while walking down the sidewalk in the winter of 1978.

She became a quadriplegic. Early on, she was very depressed. “I didn’t know any disabled people. All I knew about the disabled was the kind of infuriatingly off-the-mark stuff one is fed by the culture.”

But then she discovered the disability rights movement. She was an original employee at Access Living, Chicago’s center for independent living, when it opened in 1980. She also resumed acting and playwriting, and much of her writing had a strong disability theme. Several of her plays, such as Teletethon, Mi-

shuganismo and No One As Nasty, were produced in Chicago and other cities.

But her play Cripple Sisters, which she considered to be her breakthrough work, was repeatedly rejected for production. Nussbaum was so disheartened that she quit writing for several years. The main characters in the play were young women with disabilities. They were based on women Nussbaum grew close to during a second stint working at Access Living, where she created and organized youth outreach programs for women and girls.

Then, out of the blue, Nussbaum started writing a novel. It’s similar to Crippled Sisters in that it centers on disabled youth who are residents of a fictitious but all-too-real state-operated residential school for the disabled. In 2012, again out of the blue, she submitted her manuscript for consideration for the PEN/Bellwether Prize for Socially Engaged Fiction, an award established by novelist Barbara Kingsolver. Nussbaum won and was awarded $25,000 and a publishing contract.

Good Kings Bad Kings brings to life a world of oppressive institutionalization that is painfully familiar to many people who grew up with disabilities but that is nearly invisible to the rest of society. It is sharply political yet very funny. It is infuriating yet optimistic. The story is told through seven first-person characters, whose voices are poetic and strong and ring with resounding authenticity.

Independence Today recently spoke with Nussbaum about her life and her writing. Excerpts are as follows:

Q: After you were injured, what did you think was in store for you?

A: I was really emotionally wrecked. I was exhausted but also terrified. I thought that I would stay home for the rest of my life, and I would be in bed and just watch television forever. I would lie in bed thinking about movies that I knew had characters with disabilities, like Whatever Happened to Baby Jane? That was not a useful movie for me -- to have Baby Jane putting a dead rat under a cloche in front of her wheelchair-using sister. And the sister never got out of bed. And she was just a paraplegic.

There was all sorts of that kind of imagery. All of it was very depressing and very much about how any type of disability immediately meant your life was going to be tragic or somehow inspirational or you were going to turn into a monster because you become so bitter with anger over what happened to you. Or no one would ever love you.

Q: What changed your mind?

A: I met some disabled people. At one point, this woman came to the hospital to see me. She was my first experi-
Facebook a Real Feel-good Story

By Peter S. Kahrmann

There is no doubt that, since its founding in February 2004, Facebook has encountered its fair share of criticism, much of it fully warranted.

In April 2011, Greenpeace reported that of the biggest brands in cloud computing, Facebook relied the most on coal for its electricity. In December of that same year, Greenpeace and Facebook announced that Facebook would use clean energy.

In November 2011, Facebook reached a settlement with the Federal Trade Commission over charges that it misled its customers by failing to keep its privacy commitments. The FTC reported that the settlement “requires Facebook to take several steps to make sure it lives up to its promises in the future, including giving consumers clear and prominent notice and obtaining consumers' express consent before their information is shared beyond the privacy settings they have established.”

Personally, I think if you're online, chances are those that can and want to probably do track everyone's cyber footprints.

Despite the problems, there is a lot about Facebook I love and am grateful for. I've reconnected with a number of early childhood friends and friends from over the years. I've made connections, many invaluable, with those who share my interests -- reading, writing, advocacy, nature, etc. -- and those who fight for the same causes I do: equal rights, protecting the environment, responsible gun control, and so on.

Recently, I've been on something of a tear posting pictures of lions. The lion has become my spiritual familiar the last few years: Its ineffable spirit, appearance, and energy best mirrors my experience of self. Before the lion, it was the wolf; before the wolf, it was the bear; and before that, in childhood, it was the mongoose (Rikki-Tikki-Tavi anyone?). Fellow Facebook lovers of lions have clicked their praise, as have lovers of wolves and bears before that.

Facebook gives one the ability to join others in mourning the death of a loved one, famous or not. The recent outpouring of love for writers Maya Angelou (1928-2014) and

A Physical – and Mental – Struggle

By John M. Williams

Note: John M. Williams is a frequent contributor to Independence Today. This is the second of a two-part story about his battle with Parkinson’s disease.

Dealing daily with Parkinson’s disease, severe back pain, mobility loss and fatigue are overwhelming. So overwhelming that I ponder this question daily: Is this life worth living? My answer thus far is yes, with reservations.

My reservations are: How much of a financial and physical burden will I be to my family as I age and the symptoms associated with Parkinson’s become more pronounced? When do I say “enough” and maybe end my life with dignity?

There are a number of symptoms involved in Parkinson’s disease. Mine include the following:

Freezing

A freeze can last from 30 seconds to 15 to 20 minutes. When it occurs, both legs lock. Either I wait for the freeze to thaw, or I use an exaggerated walk to propel myself forward. The exaggerated walk involves using considerable mental effort to raise my right foot high off the ground and extend it as far as I can, and then doing the same with the left foot. I can take six steps or 50 before the freeze disappears.

Another trick to unlocking the freeze is to turn around and walk backward. My leg unfreezes, and I can walk quickly. I only walk backward when someone is with me and the ground is level.

Sometimes the freeze happens when I have not taken my medication. Fifteen to 30 minutes after I take my medication, the freeze disappears and may not reappear for hours. When the freeze happens and I am wearing my leg brace, the mental effort required to move the leg doubles. There have been situations in which I had to take the brace off before I could move. I may or may not put it back on once I get going.

I have identical braces for each leg. Sometimes I wear two braces simultaneously. I can wear them inside my pants. There are three drawbacks to my use of a leg brace. One, I can’t walk quickly. Two, I find it difficult walking up a hill and steps. Three, even though it weighs fewer than 2 pounds, after wearing it for six or more hours, it feels like a 10-pound weight. So I take it off, and only if I think I will need it will I put it back on hours later. My shoe size is 10. To wear
A Conversation With:  
NDRN Executive Director Curt Decker  
By Kathi Wolfe

Curtis L. “Curt” Decker is executive director of the National Disability Rights Network, the nation’s largest non-governmental enforcer of disability rights.

NDRN is the membership association for the federally mandated Protection and Advocacy (P&A) systems and Client Assistance Program (CAP). P&A agencies provide advocacy and legal services under all federal and state laws to people with disabilities. NDRN also engages in advocacy on disability issues ranging from voting to mental health to traumatic brain injury.

In a wide-ranging interview by phone and email, Decker, 70, discussed the twists and turns that led to his career as a longtime disability advocate, the need to work to ensure the enforcement of disability rights legislation, and other topics. Excerpts of the interview are as follows:

Q: How did you get into disability advocacy?

A: I grew up in Albany, upstate New York, and I graduated from Hamilton College (in Clinton, N.Y.). I went to Cornell Law School in Ithaca, N.Y., a very conservative law school in the 1960s. In those days, they didn’t recognize public interest law. I thought I’d be doing real estate or tax law. (But) it was the time of the Vietnam War, and I joined VISTA, a domestic Peace Corps, for a year.

I wasn’t doing it initially for the most altruistic reasons. It was pretty much to avoid going to Vietnam. You had to work in a legal entity. VISTA assigned me to Baltimore Legal Aid. It saved my life! I loved representing welfare recipients in food stamps and Medicaid hearings. I hadn’t been exposed to that in law school because they didn’t care about those things.

I had to live with a low-income black family in a ghetto in Baltimore.

Struggle  Continued from page 4

the brace, I have to buy a size 11 shoe with extra width. When my wrist and fingers were stiff, I had trouble tying my shoes. Therefore, I buy dressy, black shoes with Velcro in place of laces.

I have a separate Velcro brace for my right knee. I wear this brace when my leg stiffens. Sometimes, I wear it a couple of hours a day. Other days, I wear it longer. Sometimes, I wear it on my walks. The brace lessens the pain.

Kevin Linde, my physical therapist, helped me select the leg braces, which are made of sturdy plastic. He suggested that I wear the brace to PT when needed. I didn’t think I would ever do so, but sometimes I wear the brace during my PT.

Some days, I use two nearly identical canes on my walks. They help with my balance and speed. Linde taught me how to use a cane. I remember him saying: “Walk straight. Walk strong. Walk slowly.”

Mobility is important to me. It enables me to travel short and long distances. It gives me independence. It enriches my quality of life. It allows me to go to church, fish, go to movies, visit museums, attend parties, accept invitations to ceremonies, do face-to-face interviews, dine with my family, visit ballparks and play with my youngest son.

To keep the muscles moving and strong in my legs, every morning (except when it’s raining or snowing), I leave my home around 6:30 and return 35 to 40 minutes later. I have six different routes, and I take a different one daily so I don’t get bored. Some mornings I wear my leg brace and others I don’t. I wear my brace when my left leg is weak.

Most times, it is easy to put the brace on. Other times, I need assistance. The brace is 16 inches high and covers three-fourths of my foot. The brace serves four functions: It provides stability (I have never fallen or stumbled while wearing it), it gives me mobility (sometimes, I can’t walk without it), it strengthens the muscles in my leg, and it helps me remember to walk in a heel-toe manner. Concerning the last function, often when walking, my leg will freeze on me. To resume walking, I employ a toe-heel gait because I feel compelled to push off with my toes. Unfortunately, a toe-heel gait gets me off balance and results in a freeze.

One of the causes of freezing is sitting longer than 75 minutes. To avoid that problem, I set my cell phone to vibrate every 75 minutes. When it does, I stand up and walk around for 10 minutes. It does not matter whether I am in a meeting, at a movie, in a restaurant or in church.

Struggle  Continued on page 10
At the end of the year, (Legal Aid) offered me a job! I stayed at Legal Aid for another four years, doing everything from welfare rights to organizing.

I got involved with people who were having trouble with child protective services. When a federally funded project on child abuse came to Baltimore, I became executive director, and I lobbied for better child abuse laws. I did that for four or five years.

As that project was ending, I got a call from a friend who said, “I’m on the board of this new project created by Congress, Protection and Advocacy for Individuals with Developmental Disabilities, and we need you to take it over.”

I said: “I don’t know anything about disabilities. I don’t have a family member (with a disability).” They said: “We don’t care! We need somebody who can get the program going. You can learn the issues.” The child abuse program was winding down, and I said, “OK.” It was a year after the P&A system was created by Congress. Its main purpose was to investigate abuse and neglect. It was created when Geraldo Rivera, when he was a real reporter, uncovered the Willowbrook scandal.

And, just as I came to the P&A, the first version of IDEA (the Education for All Handicapped Children Act) was passed. Parents came rushing in, saying: “We have this new law. We need your help!” This was the case with every P&A in America.

Q: What was it like for you to learn about disability issues?

A: It was a learning curve! But I quickly got excited about the issues. It was an extension of what I was doing — (working for) civil rights. When I was at Legal Aid, I was one of the first people to do a Medicaid hearing for a transgender person (in 1978). I tried to get Medicaid to pay for the operation for a male-to-female transsexual.

I came (to the P&A) with the idea “let me learn who these people are and what their issues are.” It was a good job for a lawyer. We had good legal issues and good legal remedies.

I remember going to an institution in Maryland. The director locked me in a ward with a bunch of men with severe intellectual disabilities. He did it to scare me. If you’ve never been to an institution, and you’ve never been in a room full of people wearing these little orange suits, it was “What have I gotten myself into?” But I smiled, and they all smiled back. I realized that these fellows weren’t scary. They were just curious.

From April 8-10 this year, the LBJ Presidential Library in Austin, Texas, hosted a summit to mark the 50th anniversary of the Civil Rights Act of 1964. Four U.S. presidents attended, as well as CEOs, politicians and leaders of key organizations. Every imaginable group and discrimination issue was on the planned program except disability rights.

In the end, that omission did not stand.

Bob Kafka, national ADAPT organizer, started the ball rolling in February. When he learned about the summit, he wrote Mark Updegrove, director of the LBJ Presidential Library, and asked that the Americans with Disabilities Act and disability rights be mentioned. He received no response.

“Disability rights has always been a stepchild in the civil rights community,” Kafka noted. A short time later, he saw an article with the summit agenda that listed the broad issues covered.

“Everyone was welcome but people with disabilities,” Kafka said.

Kafka again called Updegrove and finally received a return call. Initially, the excuses kept changing. First, Updegrove said there was no time to include a separate panel, although Kafka never asked for one. Then he said that ADA was “finished law” and the summit would focus on “unfinished” law, such as gay rights and immigration. After Kafka outlined myriad examples of “unfinished” ADA law, Updegrove said that there was going
Judy Dixon has been blind all her life, and you might say the being blind part is just another of the many things at which she excels.

Professionally, she has served as consumer relations officer for the National Library Service for the Blind and Physically Handicapped division of the Library of Congress since 1981. She is a world traveler, cross-country skier, passionate cook and leading authority on braille.

Like lots of blind or visually impaired people enamored with technology and the access it provides them, Dixon has become a passionate iPhone user in the past few years. There are literally hundreds of thousands of apps available to iPhone users, and many of them, even if the developers never had anyone with a disability in mind, wind up making all manner of interesting tasks more accessible to people without eyesight.

One task not traditionally associated with blind people, though, is photography. If you’re blind, you don’t see pictures, and you aren’t likely to be shooting them either. And yet, many useful apps embraced by blind iPhone users utilize the device’s camera. There are apps to distinguish a dollar bill from a $20 bill, apps to tell you what color your shoes are, and apps to tell you if that box in front of you has crackers inside or cereal.

Dixon was using many such apps, but she also began thinking about the fact that everyone around her — sighted people, that is — was taking dozens of pictures a day, capturing images to share with friends, post online or just save for later enjoyment.

Why not me? she asked herself. Being the naturally curious sort that she is, she set out to learn how to use the iPhone camera without sight.

She researched. She studied. She took lessons from a professional photographer and, in that uncommonly clear way she has of communicating information, she gathered her findings into a singularly fascinating and useful book.

Get the Picture! Viewing the World with the iPhone Camera, published by National Braille Press, has created a buzz among a lot of people, both blind and sighted.

Whether you have ever played with the iPhone camera, and perhaps especially if you are blind or visually im-
Nussbaum  Continued from page 3

ence with peer support. This woman had a full life and was doing great in every way and was extremely active. It made me realize that things could be very different than I had been led to believe. And then, of course, the disability rights movement was taking its first baby steps in Chicago. The minute I heard about it, I had to be a part of it. I’d always been political. I’d been very active in the anti-war movement. The best week of my life almost was the first week I spent working at (Access Living). I was with all kinds of disabled people. Half the time we just laughed about how this experience was so crazy.

Q: So even before you were hurt, you had your artist side and your activist side. You continued to pursue them both but in a different way after you became disabled.

A: Well, suddenly I realized I had something to tell about this world of subversive humor and deep camaraderie and the most hilarious activism. No one knew about this. It was hidden from the rest of the world, but it was something I knew intimately. I had something to write about.

Q: In your activism, you started gravitating toward concentrating on girls and women. Why was that?

A: Because I had become very afraid for my womanhood postdisability. Was I still attractive? I was very trepidatious about becoming sexually active. I was afraid of what would happen. I was afraid I wouldn’t be a good partner. I didn’t fully understand that my sexuality was 100 percent intact. So I knew that kids who grew up with disabilities and had parents who were not disabled, which is generally the case, were much less likely than even I, who had been very sexually active before my injury, to understand that they too are sexual people. They had really not been encouraged to feel that they had any entitlement to independence or a decent education or even their own humanity, sometimes. That’s why we did that work. It was really cool because the girls just loved each other and developed a strong sense of sisterhood with each other.

Q: And then you wrote Crippled Sisters, which was very much based on this population.

A: It was all fiction, but the voices that inspired me were the voices that I heard throughout the year working with the girls. That play didn’t get picked up, and it killed me.

Q: Why was that?

A: I thought this play could be a breakthrough for me. I wanted there to be disabled writers out there who could start having an impact on this awful imagery about disabled people. So I stopped writing after that play didn’t take off. It was my first play that didn’t get produced. I was mad at everyone -- just mad, mad, mad.

Q: And so without any idea about how to do it or any previous experience, you decided to write a novel.

A: After about five or 10 years of not writing. I’d always been interested in prison abolition, and for the first time I’d begun to see that nursing homes and institutions have a lot in common with actual prisons. I realized that it’s all part of one huge system. It’s all for profit, or much of it is. It’s a cash cow for businessmen who have everything to gain from keeping a large number of people from the population incarcerated.

Q: Besides being a wonderful read, do you hope that your book will have an effect politically? Do you care about that?

A: Yeah, I do care about it. What I’m hoping is it’ll bring other disabled people into the world of fiction writing. We need to get into fiction really seriously and start setting certain standards for how disabled characters can be represented. It’s sort of like African Americans being represented by white writers. I mean, seriously. Look at the history, and you’ll see what kind of pathetic representations there were before black writers began shouldering their way in.
to be an ADA event at the George H.W. Bush Library shortly before the summit, so it needn’t be covered there.

“It seemed as if the summit was Mark Updegrove’s brainchild and creation,” Kafka said. “That made him resistant to changing his plan and including our issues.”

Marsha Katz of Montana ADAPT was not pleased. “I was taken aback by the response Mr. Updegrove gave about excluding disability rights from the spectrum of civil rights in the summit. At best, his words reveal a sad ignorance about the continuing denial of civil rights for people with disabilities, who comprise a group of upward of 50 million people in the United States. At worst, his words are a patronizing dismissal of and disregard for people who are categorically excluded from the fabric of American life in multiple ways.

“When it comes to other groups and issues the summit will address -- for example, immigration, gay and lesbian rights, racial disparities, free and appropriate public education, access to college, access to sports and athletic opportunities -- people with disabilities face more exclusion, more discrimination and fewer opportunities than any other group of people,” she continued.

Kafka suggested that Lex Frieden would be an excellent person to represent disability and ADA. Frieden is a professor of health informatics and physical medicine and rehabilitation at the University of Texas Health Science Center at Houston. He also is a professor of physical medicine and rehabilitation at the Baylor College of Medicine. He was executive director of the National Council on Disability (NCD) when the ADA was passed. He was one of the bill’s original architects. It did not hurt that he is a Texas resident.

Another hope of mine is that Gallaudet continues to expand its collaboration with other countries and organizations.

Q: What has been Gallaudet’s place for higher education in this country?

A: Gallaudet remains the only four-year liberal arts college for deaf and hard-of-hearing students. To walk on this campus is an experience like no other. Visitors witness academic discourse, friendly humor and dramatic performances -- all in a visual language. Through this fully accessible, bilingual learning environment, Gallaudet students go on to succeed academically, socially and professionally.

Alyce Slater Reynolds, Gallaudet University Alumni Association president:

Q: What challenges does Gallaudet face on this anniversary?

A: Many people, including prospective students, know little or nothing about Gallaudet. It is a challenge for Gallaudet to reach out to them.
Luther King Jr. was right when he said: “He who passes judgment without passing beyond evil.

Whatever you do, please don’t remain silent. Dr. Martin King Jr. was right when he said: “He who passes judgment without passing beyond evil.

War on Evil Continued from page 2

assessments are not done on time. They were not done on time primarily because the state didn’t provide the assessor to do the assessment!

Translation? Those with brain injury disabilities will lose the services they need to remain in the community. If they don’t like it, or they are not happy with any change in their service, they can ask for a Medicaid fair hearing. Given the symptoms some of us with brain injuries have, that is a steep, terrifying hill to climb, especially because the very same DOH has ruled that waiver staff can’t advocate for our needs at such hearings.

Gov. Andrew Cuomo can’t be the compassionate person he claims to be when his state’s DOH is savaging the lives of people with brain injury disabilities. This behavior by New York’s DOH is, in fact, evil.

In Olmstead v. L.C. in June 1999, the United States Supreme Court strongly supported the ADA’s mandate that a public entity “administer … programs … in the most integrated setting appropriate to the needs of qualified individuals with disabilities.”

ADAPT, a 30-year-old group of disability rights activists that engages in nonviolent action, has been at the forefront of fighting the discrimination and oppression of PWDs. After the Supreme Court ruling, it laid out a beautiful Olmstead implementation plan, which, in my home state and others, is often ignored. The very first item listed in the ADAPT plan is to “involve all groups concerned about developing more community services and avoiding unnecessary institutionalization.” In other words, as in ADAPT’s oft-used battle cry, it is saying “Nothing About Us Without Us!”

If you think including those whose lives are affected by laws and regulations is common sense, you’re right. But common sense rarely gets the respect and say it deserves in a culture that all too often sees PWDs as nothing more than revenue streams for evil health care providers – those who see a person with a disability as someone void of humanity.

Those of us who live with a disability have numbers on our side. One in five Americans today has a disability, which means there are more than 54 million Americans with disabilities. We are a formidable voting bloc. We are wise to use our voting power at the polls, even when the polls are not as accessible as they are required to be. Vote any way you can. It is an effective weapon against evil.

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Whatever you do, please don’t remain silent. Dr. Martin Luther King Jr. was right when he said: “He who pas-

More than a dozen times a year, while walking by myself, my legs freeze. This has happened in my bank, in several restaurants, in a movie theater, in a Metro station, on my morning walk, exiting a Safeway food store and walking to my car in a parking lot.

Once, as I was stumbling to my car in a parking lot, I was stopped by a policeman who asked to see my driver’s license. He thought I was drunk. I showed him my license. Next, he asked me to take a Breathalyzer test. I did. Nothing registered.

When my leg freezes, the rest of my body follows suit, and I become a human statue. When people see me, they ask if I need help. If I really do need assistance, I say “yes.” If I don’t, I say, “Thank you for the offer, but I can do this.” More women have offered to assist me than men.

At least three times, I have been wrong and needed help when I said I didn’t. Twice, I have been lifted off the ground and carried to a bus shelter by men who weighed more than 300 pounds. One of them was a college wrestler. The other man was a Virginia Tech lineman. Once, a Fairfax city worker put me in his car and drove me four blocks to my home.

An essential tool on my walks is my cell phone. In the event that my leg locks, I immediately call my wife or 911. Fortunately, I have not had to call her or 911.

Crutches and Wheelchair

In November 2013, I decided I needed more than my canes to help me walk. I purchased two forearm crutches and a wheelchair. I use the crutches when I am having trouble with both legs. They give me more stability and confidence than the canes. But when I use the crutches, if I had a 10-yard race with a turtle, I would bet on the turtle. I also bought an umbrella stand to keep my canes and crutches in when I am not using them.

The wheelchair is used to leave places when my legs are not working. For example, if I am at a restaurant and it is time to leave but one or both legs are giving me problems, I can ask the waiter to bring my wheelchair to my table. If I need help, I say “yes.” If I really do need assistance, I say “yes.”

Rolling Chairs

Often, it is difficult to walk from the living room to the kitchen. It was a problem moving the table chair back, then sitting in it, and then moving the chair closer to the table. To deal with this situation, I bought a small office chair. It was a problem moving the chair closer to the table. When people see me, they ask if I need help. If I really do need assistance, I say “yes.” If I don’t, I say, “Thank you for the offer, but I can do this.” More women have offered to assist me than men.

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The wheelchair is used to leave places when my legs are not working. For example, if I am at a restaurant and it is time to leave but one or both legs are giving me problems, a companion will go get the wheelchair and bring it inside so I can use it.

Rolling Chairs

Often, it is difficult to walk from the living room to the kitchen for dinner. It was a problem moving the table chair back, then sitting in it, and then moving the chair closer to the table. To deal with this situation, I bought a small office chair with wheels. Now, when I reach the table, I pull the chair back, sit in it and roll myself to the table.
had any trouble with the tapes.

The cassette recorders were 5 inches long, 2.5 inches wide and 7/8 of an inch thick. They ran on two AA batteries. The batteries lasted about eight hours. To save money on batteries, I bought a battery charger and eight rechargeable batteries. I kept four batteries charging all the time. Every time I went on an interview, I took four backup batteries and the charger with me.

The Sony recorders were easy to operate. I pressed two buttons to start recording. I pressed one to stop and one to rewind. Each recorder had a counter that went from 000 to 999. When I finished an interview, I always wrote down the numbers on the counter so I knew where to begin a second interview using the same tape. During an interview, I put the recorder close to the person being interviewed. I set the volume control on 10. The recording quality was excellent. I never had to struggle to hear the recording. When playing the recording, I used an earplug. I needed absolute quiet when listening to the speaker and then transcribing the words.

Each handheld recorder weighed less than a pound and fit easily into a pants pocket, shirt pocket or purse. A provided strap lessened the chance of the recorder being dropped and enabled me to attach it to my wrist so I could take notes while recording.

I was sold on this technology until September 2013, when I purchased an Olympus digital voice recorder.

The price for the digital recorder was $79. It is much smaller than the Sony. It is 4” long, 1.5” wide and 0.5” thick. Whereas the Sony is simple to operate, the digital recorder has 24 parts, and I thought I needed an engineering degree to operate it. There is one rechargeable battery and an on/off power switch. To charge the battery, I booted my PC and slid a USB connector on the back of the recorder into a USB port on my PC. Three hours later, my digital recorder was charged. The instructions say I can record hundreds of hours. So far, I have recorded 30 hours.

One other feature of this recorder is I can listen to music.

To record, there are five folders (A-E) that appear in a display window. I select “A” and then press the “record” button. An LED light appears in the display window. To stop recording, I press the “stop” button.

A display panel shows the recording media indicator, current file name, battery indicator, folder indicator, recorder status indicator, date, time and other information.

Four buttons appear before the display panel. They are “Stop,” “Rec,” “Erase” and “Scene Index.” Scene Index provides different background scenes to look at while recording.

To play back my recording, I select the file from the folder and press the “OK” button. To erase the file, I select it from the folder and when the recorder is in stop mode, I press the erase button. By pressing “+” or “-,” I can select to erase all the files in one folder or one file. Next, I press the OK button and then either the + or – button and then the OK button. The erasing begins.

The volume can be adjusted while either listening or recording. To improve voice clarity, I purchased a small microphone that I use during interviews.

The digital recorder is a superior product when compared to the cassette tape recorder. It is smaller, lighter, more versatile and more economical. You don’t have to buy cassette tapes and carry them with you. Because of all its features, however, the digital recorder takes longer to master. I carry the operating instructions with me, and I caution users, “If you lose the digital recorder and have not made backup files, you may lose irreplaceable data.”

I told the students, “While either recorder may meet your needs, I prefer the digital recorder.”

John M. Williams coined the term “assistive technology.” His website is www.atechnews.com.

Q: Why is this so important?

A: As long as there is nothing but bull out there about who we are, we will continue to get funny looks on the street, and there will never be systemic change. I don’t mean changing people’s attitudes. I mean the institutions of society that continue to deeply oppress disabled people. As long as the culture continues to have this idea that disability is OK as long as it’s cured, or the person commits suicide -- and I can name 50 movies in which each thing happens -- there won’t be change.

Mike Ervin is a writer who lives in Chicago. His blog, "Smart Ass Cripple," appears at smartasscripple.blogspot.com.
The things that were happening to poor people were happening to people with disabilities: benefits not coming quickly (and) all those stupid rules and policies.

Q: What have you been most proud of in your work? What’s been the most frustrating?

A: I’m proud that we have created this cross-disability advocacy. It’s allowed me to become involved in just about every piece of disability legislation that’s been passed by Congress. I was able to be part of the ADA (Americans with Disabilities Act) of 1990. That was a spectacular experience!

But yesterday, I was meeting with Amtrak people because, despite the fact that we gave them 20 years to get into compliance, it’s 2014, and they’re out of compliance (with the ADA)! We’ve been fighting with them about level boarding so people in wheelchairs can get on and off (platforms and trains). It’s hard for people who are blind or deaf to get information (from Amtrak). In a lot of rural places, you can’t even get into the stations. They basically did nothing for 19 or 20 years! We just sued them.

The ADA was the most important law in the world because everybody will end up using it at some point if they live long enough. But this Amtrak story is an example of the fact that you just can’t pass legislation and think everything is fixed. You’ve got to be there daily to make sure it keeps happening.

The most frustrating thing is: I know even though we have about $135 million of federal money, we’re probably only serving about half the people who need our help.

Q: Recently, there was a settlement with the U.S. Department of Justice (DOJ) involving the closure of sheltered workshops in Rhode Island. Why is this settlement important?

A: It builds on the statement of a federal judge in Oregon in a lawsuit brought by the Oregon P&A and others that says the Olmstead principle applies to employment. DOJ has used that ruling as the basis for the activity in Rhode Island, thus solidifying the concept that segregation is discrimination in employment as well as in residential settings. The Supreme Court ruled in Olmstead vs. LC that the ADA stood for the principle that unnecessary segregation of people with disabilities was discrimination.

The (DOJ) settlement will end sheltered employment for people with disabilities in Rhode Island over time and will serve as (a) blueprint for other states to do so as well.

Many parents are afraid of losing the workshops, so we will have to work on raising the expectations of their children and assure that appropriate alternatives are available.

Q: Do you have any hobbies?

A: I was on the board of an opera company that closed, sadly. I perform in the Nutcracker (ballet) with the Baltimore Symphony Orchestra and the Baltimore School for the Performing Arts.

Q: Thank you so much for talking with us!

A: It was fun. Goodbye.

Kathi Wolfe, a writer and poet, writes frequently on disability issues. Her most recent poetry collection, The Green Light, was published by Finishing Line Press.

I also bought an office chair on wheels for working and moving around the living room.

Battling My Legs

It is difficult to walk when struggling with both legs. For me, a Herculean mental effort is required. In my case, I have different battles with each leg.

My left leg is the weaker of the two. There are times when I can’t stand on it, and times when it will not move. When my left leg is weak and tired, which prevents me from walking, I have to sit down and put my leg on a stool for 15-20 minutes. Another remedy is lying across a bed on my stomach when my left leg is weak and tired, which prevents me from walking, I have to sit down and put my leg on a stool for 15-20 minutes. Another remedy is lying across a bed on my stomach for 10 minutes or longer. In each situation, something magical happens: I can walk, sometimes normally, for hours.

My right leg is the stiffer of the two and the most painful. When it is rock stiff, it does not want to move. Then it becomes a major mental and physical struggle to get it moving. Initially, I take small steps. Gradually, as the stiffness fades, I take larger steps. Even when my right leg is not giving me trouble, it is painful for me to walk up more than four steps. Once I reach the fifth step, I am walking up the steps one step at a time using my left leg and dragging my right leg.

My medications, when they kick in, allow me to walk almost normally.

My medications, when they kick in, allow me to walk almost normally.

Peter S. Kahrmann writes a blog on disability issues. He resides in Massachusetts.
ADAPT issued an email detailing the exclusion, which was widely distributed. At the same time, the group contacted people in the disability rights community who have ties to each of the four presidents scheduled to attend the summit: former Presidents Carter, Clinton and George W. Bush, and President Obama.

“This issue struck a nerve with our community,” Kafka said. “People felt outraged, ignored and second-rate.”

Katz agreed. “So many times we have found ourselves struggling to reactively respond to acts of exclusion, lack of access and outright discrimination. With the LBJ summit, the members of ADAPT of Texas were aware ahead of time that it was occurring, so they led a national disability effort to proactively reject exclusion and demand inclusion.”

National groups were galvanized. The National Council on Disability, National Disability Leadership Alliance and AAPD all issued statements calling on the LBJ library to include disability rights in the summit program. The ADA Legacy Project issued a press release.

In the first week of April, Frieden participated in the 25th anniversary celebration of the presidential election of George H.W. Bush at College Station, Texas. Updegrove and his wife attended and introduced themselves. “You’re a popular fellow on social media these days,” Frieden said to Updegrove. “He turned red, and his wife chuckled.”

Updegrove then asked Frieden for a big favor. In Texas, it might be called “saving one’s bacon.” He wanted Frieden to speak at the LBJ Library’s April 10 session titled “Social Justice in the 21st Century: Empowering Minds, Changing Hearts, and Inspiring Service.” Frieden agreed, but he first wanted to clarify the parameters.

“Are you doing this because you want to stave off criticism?” Frieden asked Updegrove. “Are there things you don’t want me to say?” Updegrove replied that he would never ask Frieden not to tell what happened and not to talk about things as they are.

“I thought he was candid, honest and sincere when he said he didn’t think it was important when they made their original plans because he knew President Bush was going to have a panel to talk about ADA, and there would be other events next year,” Frieden said. “There was a lot to cover, and the Bush Library was having its own celebration. He made a bad decision, and he publicly apologized.”

Updegrove told Frieden that he was welcome to participate in the entire summit. Frieden went to dinner with four presidents and attended all the social events.

Frieden was asked if he believed that his speech changed any hearts and minds on disability.

“That’s hard to say. One thing leads to another. Jesse Jackson seemed excited and interested. Lucy Baines Johnson sought me out after the panel and thanked me. She herself had been disabled, and she said she would like to help the movement. Others seemed exceptionally pleased, and several said my words had resonated with them. After the program, several people said they were going to look at plans for the future and make sure disability rights were included.”

The press coverage of his speech was extensive. The Austin American-Statesman published an article quoting Kafka on the disability right inclusion controversy, which was picked up by wire services. And several members of the disability community posted comments indicating that Frieden did a remarkable job representing them.

“It is very impressive what we can do when we work together,” Frieden said. “It wasn’t because of me. I just happened to live 150 miles away and could clear my schedule. It is remarkable that we have friends and linkages to every living president’s office.”

Frieden said that members of the disability community should never let down their guard down or take accomplishments for granted. Using the example of Uber and Lyft taxis, he said they are inaccessible and the company has stated publicly that it is not obliged to comply with ADA standards. “Imagine a Google-owned company acting that way,” he said.

Katz agreed. “People with disabilities are still incarcerated in institutions and nursing homes because our federal Medicaid policy supports that more expensive setting and does not equally support allowing people with disabilities, including America’s grandparents, to remain in their own homes and communities to receive the services they need.”

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

Article links:

LBJ Library Summit:
http://www.lbjlibrary.org/events/civil-rights-summit#sthash.IP7LYME5.dpuf

Lex Frieden’s participation in the “Social Justice in the 21st Century: Empowering Minds, Changing Hearts, and Inspiring Service” session at the LBJ Library:
http://www.mystatesman.com/weblogs/all-ablog-austin/2014/apr/10/civil-rights-summit-panel-discuss-initiatives-dire/?__federated=1

NCD statement on the LBJ Library Civil Rights Act anniversary:
http://www.ncd.gov/newsroom/04042014
Book Review

There are piles and piles of such apps – some remarkable and some not. Dixon, who evaluated hundreds of them and sorted them into categories, tells the reader exactly how each is laid out and what to expect in the way of performance.

For Dixon, what began as a curious bit of musing clearly has become a passion. One concern in publishing the book, she writes, was that she knew she was writing about a moving target. In other words, something new and revolutionary could be added to the mix the day of publication. While that hasn’t exactly happened yet, new apps are appearing and old ones are being updated all the time. To address changes and discuss photography with other blind iPhone enthusiasts, she has launched a blog called http://get-the-picture.org.

Deborah Kendrick is a newspaper columnist, editor and poet. She can be reached at Kendrick.deborah@gmail.com.

Order information

Get the Picture! Viewing the World with the iPhone Camera, by Judith M. Dixon, is available from National Braille Press, Boston, in a two-volume, soft-cover, embossed braille edition. It also is available in a variety of electronic formats, including DAISY, BRF and Microsoft Word, any of which can either be shipped (and sent via CD) or downloaded directly from the National Braille Press site. All versions are $15 each.

To read more or to order, visit http://www.nbp.org or call (800) 548-7323 ext. 520.

Consumers can go directly to the author’s blog at http://get-the-picture.org or navigate to it from the NBP site after purchasing the book.

Gallaudet

Q: Is employment for Gallaudet graduates improving?

A: Our two most recent alumni surveys say it is. Of our 2010-2011 graduates, 95 percent are either employed or pursuing additional education. As for the 2011-2012 group, 63 percent of the graduates are employed, and 35 percent are pursuing advanced studies, making it 98 percent. So the outlook is not just improving, it is outstanding!

Q: How has Gallaudet changed over the years?

A: Gallaudet has changed so much in many ways. Today, we have a much more diverse student population -- race, age, educational background, etc. -- from all over the world. There are also many improvements in terms of fields of study and internships.

Q: How did the Deaf President Now movement impact Gallaudet? How did it affect you?

A: The 1988 DPN [the protests that led to the installation of I. King Jordan as Gallaudet’s first deaf president] has created more consciousness in many different issues: political, social and employment, to name a few. In other words, deaf people have become empowered. Many more deaf and hard-of-hearing people are pursuing doctoral, law and medical degrees. During my Gallaudet days, there were no deaf school superintendents. Today, it is more of a norm to have deaf superintendents. DPN brought global attention to Gallaudet.

Brian Greenwald, professor of history, Gallaudet University.

Q: As a historian, would you talk about the history of Gallaudet -- how and why it was founded?

A: Amos Kendall, who was postmaster general during [the
terms of] presidents Andrew Jackson and Martin Van Buren, donated land in Washington, D.C., to educate a small group of deaf and blind students. The school, founded in 1857, was known as the Columbia Institution for Instruction of the Deaf and Dumb and Blind, with Edward Minor Gallaudet (EMG) as the first president. In 1864, the collegiate department, known as the National Deaf-Mute College, opened. A year later, blind students were transferred to the Maryland Institution for the Blind.

In 1866, EMG secured the services of renowned architect Frederick Law Olmstead to design the campus grounds and buildings. Women were initially accepted at Gallaudet University and eventually excluded, to be readmitted after seventeen years. African-American students were also part of Kendall School and excluded in the early 1900s to be reintegrated in the 1950s.

**Q:** Why was Abraham Lincoln interested in people who are deaf?

**A:** Lincoln signed the Enabling Act in 1864, which allowed the establishment of the National Deaf-Mute College [now known as Gallaudet University]. For the first time in the history of the world, it allowed deaf people to pursue a rigorous program of higher education in a language that was completely accessible to deaf people.

Lincoln had spoken of giving all a “fair chance in the race of life” when talking about servitude. Lincoln extolled ideas of a fair chance in democracy, and that extended to deaf students.

**Q:** What is Gallaudet’s special relationship with the federal government?

**A:** Gallaudet has had a long-standing relationship with the federal government in several ways. Every Gallaudet University degree is signed by the United States president. The first degree was signed by President Ulysses S. Grant. Degrees at commencement last May were signed by President Barack Obama.

Gallaudet University has received federal funding for the past 150 years. Currently, Gallaudet receives approximately 70 percent of its annual operating budget from the federal government. Finally, the charter stipulates that two [U.S. congressional] representatives and one [U.S.] senator are voting trustees public members.

**Andrew Morrill, Gallaudet University student body president:**

**Q:** Why did you decide to go to Gallaudet?

**A:** The accessibility and the opportunities are the reasons for me to attend Gallaudet University. Gallaudet is the place for me to feel I fit in, since everyone on campus [uses sign language], our mother hand [as opposed to mother tongue].
Most, if not all, of us know what it is to endure trauma, loss, the quicksand pull of heartbreak, with little if any support. Facebook changes that.

People on Facebook also post some beautiful quotes, phrases that inspire, lift, give hope. Two recent posts came in the wake of the passing of Mr. Garcia Marquez and Ms. Angelou:

From Mr. Marquez: “It is not true that people stop pursuing dreams because they grow old, they grow old because they stop pursuing dreams.”

From Ms. Angelou: “I've learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel.”

There is much about Facebook that makes me feel good and, during tough times, there are many on Facebook who help me feel better. I hope the same holds true for you. After all, you've got the right to feel good, be happy in life and, when days are hard, hear from those who just might help you feel better.

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

My doctor and I are experimenting with raising the levels and increasing the frequency of my use of Carbidopa-Levodopa to lessen the incidents of freezing. I am so concerned about freezing that I have restricted my travel and stopped fishing. Sometimes, I skip Sunday Mass. I skip Mass only when one or both legs are not operating together. I drive short distances (not more than 10 miles) and rarely when it is dark. So far, Parkinson’s has not impeded my memory. I pray that it does not.

Prayer is included in my daily activities. I ask God to cure me. I believe that either God has not heard my petition, or He has heard it and is ignoring it. As long as I breathe, I shall pray for divine intervention.

Speaking of God, I have had evangelicals tell me that I have Parkinson’s disease because somewhere in my family history a heinous sin was committed, and God is exacting his vengeance. Catholic women have told me, “God never gives us a challenge that we can’t endure.”

If my having Parkinson’s disease is the result of divine intervention, that’s the type of involvement I don’t need.

I know that memory loss is a result of Parkinson’s, so every day I ask myself 15 to 20 questions on various topics. For example, I might ask myself to name the first five and the last five presidents, or five great home run hitters, or five great NFL runners or five great basketball players. I might ask myself to recite the Gettysburg Address or the last five lines of Lincoln’s second inaugural address.

I sing theme songs from television shows. I recite prayers. I name my brothers, sisters, nieces, nephews and cousins and their families. I have a 25-page black notebook that I read from as I ride my exercise bike. I ask questions to myself on the content. To me, being mentally active is as important as being physically active.

My goal is to maintain my independence as long as I can. I want to drive as long as I can. I want to work as long as I can. I want to stay mobile as long as I can. I believe that eventually I will have to have a personal care assistant. I am preparing myself mentally for that eventuality. I also have forged a relationship with Visiting Angels, an organization that provides senior home care and elder care services.

I have been told there is no cure for Parkinson’s disease. This has led me to ask, “Can the medical profession cure anything?”

John M. Williams specializes in writing about disability issues. He can be reached at jwilliams@atechnews.com.