

the Independent

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Center for Independent Living, Inc.

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Righting the ADA

By *Mary C. Tintes*
Community Organizer

On July 26, 1990, President George H. W. Bush called the Americans with Disabilities Act (ADA) a “historic new civil rights Act for people with disabilities.” With strong bipartisan support, Congress enacted this law in order to create a level playing field for all by giving people with disabilities protection from discrimination in employment, transportation, public accommodations and telecommunications.

Today, in some ways, the ADA has lived up to the high hopes that accompanied its passage. Improvements in architectural, transportation, and communication accessibility have changed the face of American society. The ADA has become an international symbol

of the promise of human and civil rights, and a blueprint for policy development in other countries.

Regrettably, since the ADA passed, the employment rate of people with disabilities has not improved. In America, only 35% of working age people with disabilities are employed. People with disabilities are 2 ½ times more likely to live in poverty than people without disabilities. Worse yet, recent decisions by the U.S. Supreme Court have seriously limited the scope of the ADA by saying that people who manage their condition with medication or other treatments are “too functional” to be considered disabled and are therefore not protected by the law. This is not what Congress intended when it passed the ADA 18 years ago.

The ADA Restoration Act (H.R. 3195 / S. 1881) is badly needed to right these wrongs. You can help - contact your congressmen and urge them to support the ADA Restoration Act and help ensure

that people with disabilities have the right to be judged based on work performance. Tell them we need to restore the original intent of Congress and require the courts to interpret the law fairly. Every American wants the opportunity to work and we need the ADA Restoration Act to keep the promise to end unfair employment discrimination. ■



Freedom staff and advocates gather to watch testimony on ADA Restoration Act

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What's Wrong with this Picture?

Thresholds at doorways shall not exceed 3/4" in height for exterior sliding doors or 1/2" for other types of doors. Raised thresholds and floor level changes at accessible doorways shall be beveled with a slope no greater than 1:2. Changes in level up to 1/4" may be vertical and without edge treatment. Changes in level between 1/4" and 1/2" shall be beveled with a slope no greater than 1:2. Changes in level greater than 1/2" shall be accomplished by means of a ramp.



Disclosing your Disability at Work

By Cyndi Collins, Independent Living Advocate

When should you tell your employer you have a disability? The best time to tell an employer that you have a disability is when the time is right for you. If your disability doesn't hinder you from being successful within your position, there may be no reason to disclose the information. However, you will need to disclose your disability to your employer if you request a reasonable accommodation. According to the US Department of Justice, a reasonable accommodation is "any modification or adjustment to a job or the work environment that will enable a qualified applicant or employee with a disability to participate in the application process or to perform essential job functions. Reasonable accommodation also includes adjustments to assure that a qualified individual with a

disability has rights and privileges in employment equal to those of employees without disabilities."

Telling your employer about your disability is the only way to protect your legal rights to any accommodation you might need to perform your job. However, disclosing that information can leave you open to employment discrimination. Before revealing to your employer that you have a disability it is important to do your research. Identify any potential accommodations you might need and contact Freedom Resource Center for Independent Living for advice on how to request a reasonable accommodation. It may also be helpful to research potential employers' history of hiring people with disabilities. For example, have they hired someone with a disability before, and was the experience positive or negative? Does the employer encourage diversity in the workplace? And lastly, explore your

feelings about your disability and disclosing that information to your employer.

If you are not able to perform tasks as your peers because the work environment is hindering you, remember, it is your responsibility to disclose to your employer that you have a disability and to request a reasonable accommodation. It is not the employer's responsibility to make the assumption that you may need an accommodation because of your disability. Revealing your disability to your employer at the proper time and negotiating a reasonable accommodation can be a vital step in the long and positive employment experience. ■

Information for this article was taken from the Americans with Disabilities Act, A Guide for People with Disabilities Seeking Employment which can be found at www.usdoj.gov/crt/ada/workta.htm

From Where I Sit

By Nate Aalgaard,
Executive Director

It took me five years to get my college degree. It took me over a year afterward to land my first job. Actually, I started looking for work while I was still in college, so it was even longer than that. And this was in the mid-1980's, pre-ADA, so there really wasn't any legal protection against discrimination because of my disability. (Not that it's all that great post-ADA either. That's a whole other story, which you can read in this newsletter.)

Part of my job search included doing on-campus interviews. A number of companies coordinated with the career center to come in and interview students who were going through certain programs. I was going through the business administration program, so I had opportunities to interview with large retail corporations looking for young aspiring business graduates. One of my interviews was with Kmart. I remember distinctly how everything seemed to be going pretty good until the guy kind of leaned back in his chair and he goes something like: "Part of our expectation of all our managers is that they help unload the trucks and stack the shelves. Now I realize that might be a problem for you, but we feel it's important that our managers know all the aspects of the business." (For those of you who don't know, I have quadriplegia and use a wheelchair.)

Well wasn't that a 2 x 4 across the head? The first thing that came to my mind was, "Why the heck did this guy just waste half an hour of my time, make me dress up in this goofy-looking outfit, and take all the trouble to come over here just to tell me that?" It was a frustrating and humiliating experience to be told

that basically they didn't want me. I can still feel it – defeat. I knew I was smart enough to work at Kmart, or pretty much any other company, but I wasn't even going to have a chance.

But I did keep looking. I had a few other interviews, and nothing ever seemed to work out. One of the better possibilities for people with disabilities when I was going to college was working for the federal government. But if you recall, this was the Reagan era and federal jobs were not exactly growing on trees. Eventually I did get a job offer, with the help of some on-the-job training funding from vocational rehab, and started my career as a public relations person with a small nonprofit. At that point, even though I hadn't been formally trained in PR, I was willing to give pretty much anything to just to make some money. Fortunately, it turned into several years of employment at that organization and a couple of others. I finally got a chance to work in Independent Living, as an information specialist at Options Resource Center for Independent Living in East Grand Forks.

While there, I was lucky enough to meet Paula, who is now my wife of over 13 years.

I moved on and got a graduate degree, and then this job at Freedom, which I've had for 12 years. I'm thankful for each and every job opportunity I've had.

I think about all the people who continue to struggle for work. What keeps a person motivated after numerous rejections? What can we do as disability advocates in order to help make this better?

Employment is our number one issue for public policy here at Freedom. We're working on a number of different ideas in order to help change the system and make it



Nate Aalgaard,
executive director

better for people with disabilities who want to work. We welcome your input and your stories, as well as your efforts to educate the community and policymakers about the valuable talents that we all have as potential employees. ■

Only 35 percent of people with disabilities reported being employed full or part time, compared to 78 percent of those who do not have disabilities.

Three times as many live in poverty with annual household incomes below \$15,000 (26 percent versus 9 percent).

People with disabilities remain twice as likely to drop out of high school (21 percent versus 10 percent).

They are twice as likely to have inadequate transportation (31 percent versus 13 percent), and a much higher percentage go without needed health care (18 percent versus 7 percent).

People with disabilities are less likely to socialize, eat out, or attend religious services than their non-disabled counterparts.

Not surprisingly given the persistence of these gaps, life satisfaction for people with disabilities also trails, with only 34 percent saying they are very satisfied compared to 61 percent of those without disabilities.

Source: 2004 N.O.D./Harris Survey

The End of Sheltered Employment?

By Scott Burlingame,
Assistant Program Director and
Don Brunette, Board Member

If a person without a disability wants to go to work, they are guaranteed at least a minimum wage. If a person without a disability becomes employed, they go to work in an environment that is conducive to the job they are doing. For far too many people with disabilities, this is not true. For those among us with the most significant disabilities, the only employment options have long been in segregated “sheltered workshops” working for wages significantly below minimum wage. People with disabilities have been legally denied the basic human right to even a minimum wage and have been legally segregated while attempting to contribute to society. However, that is slowly starting to change.

In a growing number of states, disability service funding is beginning to shift towards community-based employment and away from “sheltered workshops.” Vermont has been the leader in this area of “sheltered workshop” conversion and closure. Vermont’s State Plan now states that the Division of Developmental Services funds cannot be used to increase the availability of enclaves (segregated work environments within an employer’s worksite) and cannot be used at all to fund sheltered workshops. Other states with progressive initiatives include:

Washington State: Employment for people with developmental

disabilities is shifting from segregated, sheltered workshops to integrated, meaningful jobs. Washington has been one of the most successful states in the nation in the numbers and percentage of individuals gainfully employed in jobs in communities.

New Hampshire: Since 1984, New Hampshire has not provided any funding to open new sheltered employment programs and in 1985 a systems change grant from the state Vocational Rehabilitation system helped to spur the closure of sheltered workshops.

Colorado: In 2004, Colorado developed an “Ad Hoc Committee on Employment and Community Participation”. The group had three goals: 1) Raising the priority for integrated employment; 2) Ensuring equality of opportunity for all individuals to participate in paid community employment and; 3) Promoting the use of natural supports in the workplace.

Tennessee: In 2002, Tennessee developed an Employment First Initiative. The goal of Employment First was to make employment the first day-service option and the preferred service option for adults with MR/DD. “Employment” was defined as an integrated job in a community setting that provided the opportunity to earn competitive wages.

Disability rights advocates have long believed that people should be able to receive all of their services in the most integrated environment possible. A growing number of disability rights advocates are

speaking up today that the right to earn a fair wage, in an integrated community setting, is a human right. The mere existence of sheltered workshops perpetuates unwarranted assumptions that persons with disabilities should be isolated and are incapable or unworthy of participating in community life.

If you are a person who has been frustrated by sheltered employment or subminimum wage, we would like to hear your story. Give us a call at 800-450-0459. ■

Regular or customized employment Defined in Minnesota

- *where employees with disabilities are included on the payroll of a competitive business or industry (unless self-employed)*
- *where the assigned employment tasks offer at least minimum or prevailing wages and benefits*
- *and offer ordinary opportunities for integration and interactions with co-workers without disabilities, with customers, and/or the general public*

Read the entire Minnesota Employment First Consensus Report at

[www.mnapse.org/
Employment-First-Report.pdf](http://www.mnapse.org/Employment-First-Report.pdf)

Employment-related Independent Living services expanded in Becker and Otter Tail Counties

By Nate Aalgaard, Executive Director

A new collaborative effort between Freedom Resource Center and Rehabilitation Services in Minnesota will address unmet needs of populations within portions of Freedom's service area. A grant from the state will allow Freedom to add another staff person specifically to address employment-related needs for individuals in Becker and Otter Tail Counties. Becky Waldera will be the Independent Living Advocate staffing this new program. Her office will be based in Fergus Falls and she will spend two days per week in Detroit Lakes. She will primarily work with adults who are in need of employment related services, or youth with disabilities who will be transitioning from high school to independent living or work.

Although Freedom has had an office in Fergus Falls for several years, there are individuals with disabilities who may not be aware of or utilizing the Center's services. Freedom has provided some service in Becker County, but has not had the resources for a consistent presence in the county, leaving people with little or no understanding of what the Center could actually provide. This collaborative effort will lead to improved access to services for people in both counties.

Specific services could include:

- Independent Living Skills Training
- Individual Advocacy relating to transition from school to work or adult independent living
- Plans to achieve self-support (PASS)
- Training and advocacy for individuals regarding employment discrimination
- Individual or group job seeking skills training; including resume preparation, interviewing, and workplace accommodations
- Social Security Administration work incentive information and benefits counseling
- Assistance with addressing barriers to employment such as transportation, housing, or technology
- Systems advocacy relating to employment

For more information on this new program, please contact Freedom in Fergus Falls at 218-998-1799 or Detroit Lakes at 218-849-3988.

Assistive Technology Low Cost, Low Tech Item of the Month

Item:
Automatic Jar Opener.
Opens jars at the touch of a button.

Price:
\$19.99

Find it at:
Bed, Bath and Beyond
Also available at Target.



Information

In an attempt to reduce the cost of mailings please send your email address to freedom@freedomrc.org

If you would like to be removed from our mailing list please call 701-478-0459 or 1-800-450-0459.

Freedom Resource Center and/ or its Board of Directors do not necessarily endorse or support any of the views expressed within the personal testimonies contained in this newsletter, unless approval is specifically mentioned.

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Alternate formats available upon request.

Editorial Board: Nate Aalgaard, Scott Burlingame, Cyndi Collins, and Rikki Trageton

Susan's Journey with Disability

By Rikki Trageton, Independent Living Advocate

Susan Wedberg is 59 and lives in Fargo. She was diagnosed with multiple sclerosis (MS) in 1989. Susan worked full time, raised a family, and lived an active independent life in spite of her disability. As her condition deteriorated and her spasticity worsened, she decided in August 2001 to undergo a surgical procedure to insert a baclofen pump into her abdomen. This pump would automatically dispense medication and help control the spasticity associated with her MS. When the pump was installed, unfortunately there was a misdose of medication. The misdosing of the medication left Susan a quadriplegic. Her MS is now a secondary disability to the quadriplegia.

Due to the quadriplegia, Susan requires the 24-hour care from another person. Currently Susan must pay out of her own pocket for all of her own personal care. These personal care expenses cost more per month than her monthly income. In addition to her personal care expenses, she also has regular living expenses for food, clothing, and shelter that everyone else has.

Why does Susan have to pay all of these expenses herself you ask? Her insurance companies, Tricare and Medicare, do not pay for personal care assistance or "custodial care" as the insurance companies call it. Susan's income is over the allowable limit to qualify for assistance from social services or the ND Department of Human Services. Susan is not eligible to

purchase long term care insurance because of her diagnosis of MS. She is stuck in a "catch 22." Her insurance companies do not cover the types of services Susan needs unless a person purchases long term care insurance.

Susan's wish is to be able to remain living in her home in the community and stay out of a nursing home. When her resources are depleted, this will no longer be possible. She will be unable to continue to pay for her personal care expenses and will end up with no choice other than going into a nursing home and becoming a liability to the state.

Susan's story potentially impacts a large number of people. Military service personnel and their spouses are covered under Tricare or some branch of it as their health insurance. Consequently, if a veteran becomes disabled, and has not purchased separate insurance, he/she will have the same option as Susan; pay out of pocket for services or go to a

nursing home. Many other private insurance companies such as Blue Cross Blue Shield also do not cover "custodial care." Additionally, anyone who is disabled and whose income is over the limit to qualify for medical assistance faces the same fate.

What can we do? Advocates, people with disabilities, service providers, and the general public need to start speaking out to insurance companies and federal government entities like Medicare and Tricare and demanding funding for home and community based services for people who wish to stay out of institutions and remain in their communities.

"Never doubt that a small group of thoughtful committed people can change the world. Indeed it's the only thing that ever has." Margaret Mead. ■



Susan Wedberg and Family

Social Security Backlog

By Scott Burlingame, Assistant Program Director

At Freedom, we have seen many people frustrated by the bureaucracy that is the Social Security system. On January 14th, Congressman Earl Pomeroy, (D-ND) held a stakeholders meeting in Fargo to discuss the Social Security backlog. Nate Aalgaard and Scott Burlingame were able to attend this meeting and tell the Congressman about the struggles we have seen with the Social Security backlog and provide him with input on the changes we believe need to be made. Among the things we told the Congressman are:

The current application and appeals process is extraordinarily long and extremely inefficient. People with even the most significant disabilities take several months to get benefits, and we have just seen a case that took 33 months to get approved.

Insufficient funding of the Social Security Administration (SSA) has resulted in poor

quality services. This has led to delays in processing applications and appeals, earnings reports, continuing disability reviews, and waiver requests. On numerous occasions, people have reported having information lost in the Social Security system. Many people have also reported that SSA and the state Disability Determination Centers made determinations on disability without gathering information from all reported medical sources.

The Social Security Administration's rules, regulations and policies are overly complex and have created a bureaucratic barrier for people attempting to receive or manage benefits. SSA staff have given incorrect or incomplete information to applicants, beneficiaries, and recipients. People have constantly been frustrated by the amount of redundant and confusing forms they are asked to fill out.

At Freedom Resource Center for Independent Living, we support additional funding for the Social Security Administration to hire more

staff. However, we feel that all new funding should come with the mandate for reform. We feel...

- the Social Security Administration should enact reforms that simplify their rules, policies and practices.
- that SSA staff should be trained and required to assist more in both the applications and appeals process.
- the state Disability Determination Centers should work closer with the applicants to ensure that all medical documentation is taken under consideration, and that all alleged disability claims are thoroughly investigated prior to any denials.

If you are a person who has been frustrated by Social Security backlog, we would like to hear from you. Give us a call at 800-450-0459. ■



Former Freedom board member Christine "Chick" Kastrinos passed away at her home in Fargo on January 31, 2008 at the age of 37. She was injured in a car accident in 1996, which left her with quadriplegia. She used a ventilator to breathe. Her mother, Elaine, was her full-time and constant personal assistant and soul mate. They, along with Chick's dad Larry, faithfully attended board and committee meetings for six years. Because of Chick's disability, getting out of the house could often be physically quite challenging. Cold weather was especially a problem, but she was always determined to take part. Everyone who knew Chick would readily acknowledge that she always had a positive attitude. She never complained even when things got bad and she encountered health problems. Chick's life exemplified determination, dedication to the cause of disability rights, and the loyalty of friends and family. She will be dearly missed.



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The Mission of Freedom Resource Center for Independent Living is to work toward equality and inclusion for people with disabilities through programs of empowerment, community education and systems change.

We envision a society where ALL individuals are valued, respected and have equal opportunity, access, responsibility, and freedom of choice in all aspects of life.

Civic Engagement Opportunities

April 14 (1:30 – 4:00 pm) MeritCare Health System **Living Well Workshop** – First of six sessions on learning to live with the effects of a chronic condition – St. John's Lutheran Church, Fargo – FREE, but registration is required. Call (701)234-5570 or (877)237-4240

April 23-25 – **22nd Annual NDACF Conference, "Transforming Values into Action"** – Doublewood Inn, Fargo - discuss emerging employment options, inclusive community supports and systems advocacy – Financial assistance applications available

July 24 – "**ADA Celebration**"–Lindenwood Park, Fargo - community celebration of the 18th anniversary of the signing of the ADA into US civil rights law. For more details, contact Rikki Trageton or Scott Burlingame at Freedom RCIL (701)478-0459

September 18 (7:00 pm) – **19th Annual Celebration, Freedom Resource Center with keynote speaker, Billy Altom, Executive Director, Association of Programs for Rural Independent Living (APRIL)** – Ramada Plaza Suites, Fargo –hear the compelling story of how a bluegrass musician from Arkansas became a leader in the disability rights movement.

September 19 (9:00 am – 2:00 pm) **Billy Altom, (Workshop – Training)** learn how to become involved in disability rights and systems change in your community from an expert in the ADA!

Watch for information on candidate forums and Leadership Training 2008 in Fargo and Jamestown areas. Call Mary at (701) 478-0459 for more information