

# *the* Independent

A Publication of Freedom Resource  
Center for Independent Living, Inc.

Summer 2008

## A Profile in Breaking Out

By Susan Taylor and Cyndi Collins,  
Independent Living Advocate



*Susan Taylor*

This is a story about Susan Taylor, a young woman who left a nursing home and is now living independently. In July of 2007, after a period of illness, she was taken by ambulance to the hospital where she underwent much testing and her condition deteriorated into complete paralysis. Three weeks later, Susan was transferred to a local nursing home where, for 7 months, she received physical and occupational therapy. She has little memory of her first months at the nursing home. Once she regained strength, she wanted to relocate from the nursing home. She contacted Freedom Resource Center to assist her because transitions from the

nursing home are not always easy. The care team tried to push Sue into living in a group home, saying that if she moved into her own apartment, she would fail and end up back in the nursing home. They were judging her potential success based on her disability, not on the services and supports out there to help her live independently. Then Sue discovered that in June of 1999, the U.S Supreme Court ruled that the ADA forbids states from institutionalizing people with disabilities if they can live in their community with community-based support services.

When Sue found out about the 'integration mandate', she got an apartment! She planned for discharge and left the nursing home that day. Sue learned how to manage her daily medication independently and completed outpatient therapy. It was thought that Sue would never walk, but she is. She still has little feeling in her legs and hands and she's recovering from 14 months of amnesia. Her illness continues to be an undiagnosed mystery. Sue said, "There are things in daily living that are so hard and frustrating. It takes me a good while to tie my shoes and I open pop cans with a screwdriver or pen. Sometimes it takes me several minutes to get my seatbelt to release and I wonder sometimes if I'm going to be stuck in my car." However, Sue says she has a never-ending sense of humor and finds her moments of weakness to be 'laugh out loud' funny sometimes. At times, she feels

depressed, but she attends counseling and keeps trying to improve her life. She seeks for new ways to live as a person with a disability. She said, "I keep the faith and go on with life the best I can."

Freedom Resource Center assists people in relocating from institutional settings back into the community. We believe that the level of community supports available will determine the success of the transition, not the type or severity of the disability, and that appropriate supports and services are vital to a person's successful relocation. Services may include health services, social supports, housing, transportation, volunteering/employment opportunities, advocacy, and financial resources. We believe that if given the dignity of risk, if given a chance, people will succeed in their community.

If you wish to help, a benefit account has been set up for Susan Taylor to help defer her medical expenses. It is at Choice Financial, 4501 23rd Ave S Fargo ND 58104. ■

*Focus on Home and  
Community Based Services*

### What's Inside

- What's Wrong with this Picture
- Five Wonderful Months
- Legislative Update
- The Right To Live At Home
- How Will I Pay For My Services?

## What's Wrong with this Picture?

It is either:

- A) Two people with mobility impairments just bought brand new cars and haven't driven them home yet.
- B) This business has its accessible parking sign in the wrong place.
- C) They have little consideration for potential customers with mobility impairments.



## Five Wonderful Months

By *Nate Aalgaard*  
Executive Director

He had the perfect name for someone in real estate – Sell. And sell he did, over a 35-year career as a successful real estate agent and owner in Moorhead. Leon Sell was known as a hard worker, a loyal and dedicated family man, a fun guy to be with. Freedom's Board President, Larry Chial, worked with Leon for a time at Wagner Realty. "If it was late on a Friday afternoon, most people would take off. But even if he had sold five houses that week, Leon would still be there working on another deal," Larry said.

A fall from a ladder and subsequent paralysis drastically changed his life in 2003. He spent four years in a nursing facility, finally getting home in March of 2007. On April 10, 2008, Leon Sell, 71, passed away following eight months of hospitalization as a result of complications from a car accident, which happened in August, 2007. That accident was a tragic event that cut short what his wife Judy

called, "Five wonderful months."

Leon was a persistent guy. And that persistence helped him make arrangements to leave the nursing facility and return home. He had built an accessible house. He bought an accessible minivan with a lowered floor and hand controls, and he had learned how to drive it. He put ads in the paper and found nurses and personal assistants to come to his home and help him morning and night. He purchased a vast array of durable medical equipment of all kinds to help make his life better.

According to Judy, the summer of 2007 was just great. Leon spent a lot of time driving around in his van, taking his grandkids to the lake, and visiting friends around town. "That van was a godsend," she said. He even got to be sort of a daredevil at the lake. He would go down and sit at the end of the dock in his power wheelchair. "He scared us to death," Judy said. "He would go out there and fall asleep and he would leave the power on his chair on. We were afraid that he would bump it and go right off the end.

We couldn't tell him not to do it. That's one thing about Leon. He would always do it anyway."

It was all cut short on August 30, when Leon, stopped at the stop light on Highway 10 right by Wal-Mart in Detroit Lakes, was rear-ended at high speed. Fortunately, the grandkids were not with him this time. His van went into the median and across the oncoming lane of traffic, coming to rest only a short distance from a rail car. His van and chair were both totaled. He had broken legs and a broken arm, serious bumps and bruises, and

continued top of p3



*Leon Sell*

internal injuries. His kidneys failed, which forced him to go on dialysis. His arms also became somewhat paralyzed. He could no longer feed himself, brush his teeth, or comb his hair. He spent the next few months in the hospital. He knew he was in really bad shape. After such a long struggle the first time around,

he just didn't see much in the future for himself, knowing he would not be able to drive again.

He kept his spirits up though, and his mind stayed extremely sharp. He enjoyed visits from friends and family, and was determined to hang in there until his birthday on April 7. On April

10, Leon finally succumbed to the infection and tremendous stress that these injuries put on his body.

Even though Leon had to endure two tragic accidents that eventually took his life, Judy still looks at the positive. "I'm so glad he had the chance to come home, even if it was just for five months.

## From Where I Sit

*By Nate Aalgaard,  
Executive Director*

My grandparents ran a nursing home for several years. My grandpa had the title of superintendent, the official leader of the organization. But it was my grandma, as the administrative assistant, who really ran the place. She was the educated one. He was the PR guy.

Admitting that my family ran a nursing home might be dangerous to say, when you're in the disability rights movement and working at a Center for Independent Living. But I feel I need to make that point, because my personal belief is that they did the best they could to make it a homelike environment, given the situation, the time period, and the people they were working with. This nursing home, Pioneer Home in Erskine, Minnesota, had at that time the mission of taking people out of the state hospital in Fergus Falls, and bringing them to their facility. At that time, it was far and away better for them to be in a small community nursing home than a large state institution. Families simply did not have the resources they needed to take care of people who were chronically mentally ill at home.

But times change. I know for a fact that I don't want to ever go to a nursing home. My dad has said

pretty much the same thing. Today, with advancements in medications, equipment, and technology, people have more options. Most of us should never have to face the reality of only having the choice of a nursing facility when we need long-term care or supports. And that's what it is all about – choice.

Recently, there have been stories in the media about Minnesota nursing homes facing a crisis in funding. Some have closed. The facts are that most people do not want to end up living in nursing facilities, and it is generally less costly for them to live at home. The state of Minnesota has made great strides in developing a comprehensive system of providing home-based services to people with disabilities and those who are elderly and need assistance. In fact, Minnesota is generally regarded as one of the best in the country.

But as with most programs, they can always be better. Freedom is working on a one-year grant to enhance our ability to provide nursing facility relocation and prevention services in Minnesota. We had a training session, in cooperation with Options Center for Independent Living in East Grand Forks. We brought in national-level trainers for three days to teach us about the process. Our next project is to develop outreach materials



**Nate Aalgaard,**  
executive director

so that our staff can use them to provide information to people in our service area about the options for living in their homes and local communities should they ever need long-term care or supports. Our efforts in North Dakota are centered around the Money Follows the Person proposal that the state has sent to the federal government. All the Centers in North Dakota have been actively involved in helping to plan and put together this program.

Living in the home and community of your choice is a basic human right. The disability rights movement has put this at the forefront of its national agenda. We believe everybody deserves that freedom. ■

# THE RIGHT TO LIVE AT HOME

By Rikki Trageton, *Independent Living Advocate*

When I met “Joan”\* she was a 72-year-old patient in a local hospital. She contacted Freedom Resource Center on the advice of her daughter, “Betsy,”\* after being told by her doctor that she was going to be discharged from the hospital into a nursing home. Joan did not want to go into a nursing home. She wanted to return to the home she owned and had lived in since 1962. Hospital staff told her she had no choice, because her home was not accessible and she could not return to it.

Staff from Freedom met with Joan and her family and informed them of Joan’s right to live in the least restrictive environment. Joan stood up to her doctor and told him she would not go into the nursing home and she would be returning to her home.

The reason for Joan’s hospitalization was a second amputation. Prior to this, she used a prosthetic device and did not have the need for a wheelchair. Following the second amputation, Joan would need to use a wheelchair. The reason Joan’s doctor wanted her to go into a nursing home was her home was not accessible. But she did not need the level of care provided in a nursing home. Joan lived completely independently prior to this recent hospitalization, even driving and mowing her own lawn.

Joan and an advocate from Freedom worked together to begin

making Joan’s home accessible. First, an “accessibility survey” was conducted to evaluate the changes that needed to be made to Joan’s home to make it accessible. Second, Joan and her advocate set out to find community-based resources to assist in funding the accessibility remodeling. Joan needed a ramp on her home, doorways widened, and her bathroom remodeled to accommodate her wheelchair. Applications were accepted by programs at SENDCAA and the City of Fargo to assist Joan. Joan left the hospital and returned to her home.

That was two years ago. Today Joan continues to live

independently in her home, and receives no other services. She has family members who assist with laundry, yard work, and heavy cleaning. She is able to continue to enjoy community-based living in the home in which she raised her family.

Joan says, “Almost ending up in a nursing home was one of the most frightening things I’ve ever been through. The staff at Freedom helped me out a lot and I am very happy with the services I received. If I wouldn’t have called you (Freedom), I might be in a nursing home today.”

\*Consumer’s real names have been changed at their request.

## Celebrate The ADA Thursday, July 24th

4pm - 7pm  
Lindenwood Park  
Fargo, ND

**CELEBRATE THE 18TH ANNIVERSARY  
OF THE AMERICANS WITH DISABILITIES ACT**



Chamber of Commerce Ribbon Cutting  
Commemorative Walk to Support the ADA

**FREE PICNIC**

For questions, call Freedom at 701-478-0459

# Legislative Update

By Scott Burlingame,  
Assistant Program Director

Legislative Update Support continues to build for the ADA Restoration Act. First on March 13, the National Epilepsy Foundation rescinded their membership in the SHRM (Society of Human Resource Management) because of SHRM's position against the ADA Restoration Act. On May 1, a group of 25 national Communities of Faith Organizations sent a letter to Congress urging them to support the ADA Restoration Act. In addition, 21 veterans and military organizations have signed letters to Congress supporting ADA Restoration.

The Farm Bill has passed Congress, has been vetoed by President Bush, and Congress overturned the veto (now due to a clerical error, the whole process is being repeated, however, it is expected to soon become law). This matters to people with disabilities in North Dakota and Minnesota not only because of agriculture's effect on our economy, but also because the USDA Rural Development 502/504 housing programs and community block grant and community development money is also included in the Farm Bill. The bill calls for more than a \$10 billion increase to the nutrition title, which is responsible for the Food Stamp Program and the Emergency Food Assistance Program. This will help more than 27 million Food Stamp Program participants across the country manage rising food costs.

Minnesota lawmakers passed a plan to increase the state's minimum wage. Governor Pawlenty vetoed the bill, and his veto was not overridden. It did not appear that this bill would have included a mandatory minimum wage for the Minnesotans with disabilities working on subminimum wage jobs. Minnesota could learn from Arizona, which passed a 2006 referendum promising minimum wage for ALL employees.

Finally, as we focus on Home and Community Based Services (HCBS) in this newsletter, it is important to note that the Federal Center for Medicaid and Medicare Services (CMS) has undertaken a "rebalancing effort" of long-term care services with the goal of balancing HCBS with Nursing Home Services. In Minnesota, the news is good, as in 2006 they came close to a 50-50 split. North Dakota on the other hand, is one of the most unbalanced states in the nation, as about 90% of funding goes for Nursing Homes and other institutional settings. ■

## Assistive Technology Low Cost, Low Tech Item of the Month

**Item:**  
Ring Pull Can Opener

**Price:**  
\$3.99

**Find it at:**  
Bed, Bath and Beyond



# Information

In an attempt to reduce the cost of mailings please send your email address to [freedom@freedomrc.org](mailto: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

# HOW WILL I PAY FOR MY SERVICES?

*By Rikki Trageton and Cyndi Collins,  
Independent Living Advocates*

North Dakota and Minnesota have home and community based programs available to people with disabilities. These programs vary greatly between the two states. Home and community based programs were designed to provide needed services and supports to people with disabilities. Waiver services need to be an alternative to institutional placement, be necessary to ensure the health, safety and well-being of the person, increase a person's independence, be based on an individual's need, and not have any other funding source. This article will attempt to provide basic information to readers about what is available in each state and contact information for where to go to see if you qualify.

## Minnesota

In Minnesota, to be eligible for a home and community based waiver, a person must be eligible for medical assistance and certified disabled by Social Security or by the State Medical Review Team (SMRT). Minnesota's home and community based programs include the following:

CAC (Community Alternative Care), CADI (Community Alternatives for Disabled Individuals), DD (Developmentally Disabled and related conditions), TBI (Traumatic Brain Injury), CSG (Consumer Support Grant), FSG (Family Support Grant), Home Care Services-skilled nursing, home health aide, private duty nursing, & therapies, ICF/MR (Intermediate Care

Facility for Persons with Mental Retardation or Related Conditions), PCA (Personal Care Assistance), SILS (Semi-Independent Living Services).

Services available through each of these programs in Minnesota vary greatly and are based on individual need. Services may include things like assistance with personal care, help with shopping and budgeting, mental health behavior aides for children with special needs, respite care for family members, and vocational supports. To see if you qualify for Medical Assistance and/or one of these program's contact your local county social service office.

## North Dakota

In North Dakota, options for paying for home and community based services include the following.

First is the Medicaid Waiver for Home and Community Based Services. In order to be eligible, a person must be Medicaid eligible, be 16 years of age or older and be physically disabled or be at least 65 years of age. A few examples of services available are; adult day care, homemaker services, non-medical transportation, respite services, home delivered meals and family personal care.

Next is the Technology Dependent Medicaid Waiver, a program that is only provided to individuals who are ventilation dependent. In order to be eligible for the program, you must be Medicaid eligible, be 18 years of age or older, have a physically disability, be medically stable and be vent dependent at least

20 hours per day. Services included with this program are nursing management, attendant care service providers, and case management.

Another option is Expanded Service Payments for the Elderly and Disabled (EX-SPED). To be eligible for this program a person must be Medicaid eligible, and be impaired in three of the four following Activities of Daily Living (ADL): Meal Preparation, Housework, Laundry, and Medication Assistance and cannot be severely impaired in ADL's, (Toileting, Transferring, or Eating). Some services provided under EX-SPED are, homemakers, chore service, family homecare, and emergency response system.

Service Payments for the Elderly and Disabled (SPED) is another program offered by the Department of Human Services. A person must meet the financial eligibility of income and assets at a sliding fee scale. They must be impaired in four of the ADL's, Meal Preparation, Housework, Laundry, and Medication Assistance or, if under the age of 18, screened for nursing facility care; and impairments must have lasted or are expected to last three months or more. Some services provided under SPED are: respite, HCBS case management, environmental modification, adult day care and family home care.

It's important to call your county social worker to see if you meet the qualifications for each program. Only your county social worker can provide the proper screening and assessments to determine your eligibility. ■

## The self pay option for personal assistance

By Nate Aalgaard, Executive Director

If a person is not eligible for publicly-funded personal assistance services because of financial or other eligibility issues, self-pay could be a viable alternative. Benefits of self-pay are:

- Flexibility in scheduling
- Less restriction as far as duties that can be performed by the personal assistant
- Direct control over who you hire
- Payments for personal assistance may be deducted from your income tax as a medical expense

There are several options for finding good private pay personal assistants. One way would be to place an ad in the newspaper. Another would be to ask other people who you know use personal assistance, to see if they have any referrals of people they know who are looking for work. You may also possibly post notices at colleges, or at the local Job Service office or Workforce Center.

In order to enhance the chances of everything going well, you may want to consider conducting a background check on the person, and calling references of previous employers or clients. Be aware that many references may be personal friends or relatives, so take information from them with a grain of salt. The best referrals come from other people who have directly worked with that person.

Two or three hours a day of private pay personal assistance can mean the difference between independence and the possibility of having to move to a more restrictive environment. Many times it is not all that costly. The rewards can definitely far outweigh any expense. ■

## Consumer rights in nursing homes and group homes

By Rikki Trageton, Independent Living Advocate

### IF YOU OR A FAMILY MEMBER LIVES IN A NURSING HOME OR GROUP HOME YOU HAVE THE RIGHT TO:

1. Access to Information
  - on services available to you and charges for those services
  - on facility policies, procedures, rules, & regulations
  - contact information for the state ombudsman
  - daily communication in your own language and access to assistive technology if needed
2. Participation in Care
  - receive adequate care
  - refuse medication or treatment and be offered alternative treatments
  - participate in discharge planning
  - review own medical records
3. Ability to Make Choices
  - choose your doctor
  - take part in activities in the facility and community
  - be a part of a resident's council
  - manage personal finances
4. Privacy and Confidentiality
  - private, unrestricted visits with family, friends, and other residents
  - access to any agency providing health, social, legal, or other services
  - confidentiality regarding all personal, medical, and financial information
5. Dignity, Respect, Freedom
  - be free of mental and physical abuse
  - be free of chemical and physical restraints
  - file complaints of suspected abuse or neglect
6. Complaint Procedures
  - right to present grievances to staff or others without reprisal
  - have grievances promptly resolved by the facility

[www.medicare.gov](http://www.medicare.gov)  
[www.nursinghomealert.com](http://www.nursinghomealert.com)



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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

June 19 (9:30 am – 3:00 pm) **“Becoming a Leader in the Advocacy Movement”** – Jamestown Business Center, Jamestown, ND – Learn and build skills in public speaking, community education, building allies and promoting systems change. Free and open to the public. For more details or to register, call Andrea Nelson at (701)252-4693

August 7 (10:00 am – 4:00 pm) **Youth Leadership Training** – Chahinkapa Park, Wahpeton, ND – Open to ND & MN residents ages 14 – 22; learn to become a strong self-advocate and a leader in the disability rights movement. For more information or to register, call Micara Kverno at 1-800-450-0459. Class size is limited, so register early!

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 MN Candidate Forums this fall.**

**Check our website for updates- [www.freedomrc.org](http://www.freedomrc.org)  
Call Mary @ (701)478-0459 for more information and volunteer opportunities**