

FREEDOM



Freedom Resource Center for Independent Living, Inc.

Summer 2004
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Issue 3

Mission Statement

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.

Vision Statement

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

Legislative Update:

Five Years Post Olmstead

By Chuck Stebbins

When Tommy Olmstead was named the defendant in a case brought by two women in Georgia who were sick and tired of being institutionalized, he probably had no idea that his name would be synonymous with, "Get me outta this nursing home!" Well, that may not be the correct use of synonymous, but you'll get the idea in a minute.

For those who do not know the history of the Olmstead Decision made by the Supreme Court in 1999, Tommy Olmstead was the director of the Department of Human Services in the state of Georgia. The lawsuit was filed by two women who were left to live in institutions, despite the opinions from treating professionals that placing them out in the community was appropriate. Crucial to the case was the fact that the state of Georgia did not administer its Medicaid program, in the words of Justice Ginsberg, "with an even hand."

The Center for Medicare and Medicaid Services (CMS) had approved 2,100 community-based "waiver slots" for Georgia. The state chose to fund only 700, thereby leaving seriously underfunding the very portion of its approved plan that would have made community integration feasible for those institutionalized.

It was ground-breaking stuff, violating Title II of the Americans with Disabilities Act that said services need to be provided in the least restrictive setting possible. This decision marked the first time that the Court had interpreted the ADA in a way that directly impacts Medicaid, and how and where services can and should be delivered. It was history-making for people wanting to stay in their own homes and communities. This was now a Supreme Court decision that allowed people with disabilities to use the ADA as the civil rights law it was intended for.

But, what about its impact? Following was taken from a report done by the Kaiser Foundation. It's not all of it, just some highlights. If we were to print the whole thing, first of all, we wouldn't have the

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Essay Contest

Freedom Resource Center has a vision to create a community that is just and fair and that empowers people with disabilities. You can help us create this vision by submitting essays for what we hope will be an annual essay contest. Freedom Resource Center is accepting essays addressing the subject "*Creating a Community That Empowers People With Disabilities.*" The winning essay will be printed in Freedom Resource Center's fall newsletter and will be presented by the author at Freedom Resource Center's annual meeting, September 23, 2004. Honorable mention winner essays will be published in upcoming newsletters. The essay must be within 800 -1,200 words. Entries must be postmarked no later than August 31 and mailed to:

Essays, Freedom Resource Center, 2701- 9th Ave SW, Fargo, ND 58103.

What's Wrong with this Picture?



There is no access route that connects the accessible parking area with the entrance of the building; the access route needs to be stable, firm, and slip-resistant.

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From where I sit

By Nate Aalgaard, Executive Director

There is a well-used political cliché, "Are you better off today than you were four years ago?" As it relates to people with disabilities, are we better off today than we were four years ago, or eight, or ten, or more? We've had the ADA for 14 years. Other laws and initiatives are also intended to help us become more equal participants in community life. But is it working?

The National Organization on Disability has been surveying the status of Americans with disabilities since 1986. They recently came out with their latest version, the 2004 survey. It tracks a number of different factors of everyday life, such as employment, education, socializing, income, access to healthcare and transportation, and overall satisfaction with life. It really does give a very good picture of what it is like to live in the United States and have a disability.

The survey this year shows that some of the factors surveyed have gotten better for people with disabilities, some worse. In particular, 35 percent of all people with disabilities now work either full or part time. This compares to 32 percent four years ago. But if we go all the way back to 1986, 34 percent were employed. The difference is striking between those who have somewhat or very severe disabilities and those with slight or moderate disabilities. Those with severe disabilities have only 21 percent working while slight to moderate is 54 percent. This compares to a 78 percent employment rate for people without disabilities between the ages of 18 and 64.

Twenty one percent of people with disabilities do not graduate from high school. This number has decreased over the years from a beginning rate of 39 percent in 1986. Overall, 11 percent of the general population does not graduate from high school.

Seventy nine percent of people with disabilities socialize with close friends, relatives or neighbors at least twice a month. This is down slightly from the level of 2000, which was 81 percent. The population in general has an 89 percent rate of socializing. A couple other major findings in the study is that in the past year, 24 percent of people with disabilities reported at least one occasion where they did not get necessary healthcare. This compares to only 7% of those without disabilities. In addition, people with disabilities are over twice as likely to lack adequate transportation.

Probably the most disconcerting finding in this study is that over the last few years, the percentage of people with disabilities who are very satisfied with their life in general has not gone up. It is only 34 percent, compared to 61 percent for those without disabilities.

“Progress is too slow, and the gaps are still too large,” said National Organization on Disability President Alan A. Reich. “Looking back four years or ten years to our earlier surveys, we see Americans with disabilities heading in the right direction, but people with disabilities remain pervasively disadvantaged. Our goal of full participation is a dream deferred. I hope that the findings we are releasing today will inspire legislators, public officials and the American people to rededicate themselves to this goal. A fifth of Americans have disabilities; everyone knows people with disabilities; and anyone can acquire a disability at any time. Everyone has a stake in these findings.”

One very interesting finding in addition to all of the other statistics is that people with disabilities now have more of a common sense of identity with other people with disabilities. That rate is now 56 percent compared to 47 percent in 2000. What does this mean? I think it means we have many similar issues: jobs, transportation, access to communication, or isolation because of various factors in the environment. And maybe, just maybe, we’re starting to identify that we can become a group that can influence public policy together.

To use another very familiar line, I have a dream, that someday public policymakers will be calling us and asking us what they should support in their political platforms and when they go to vote. Wouldn’t that be great!

What’s in Your Future?

By Gyle Peterson

In light of my future situation, I sometimes wish I were a tree in the Amazon Forest that was sentenced to the axe, or a dying beached whale on the Pacific coast, or maybe even an insect on the Endangered Species List. Am I crazy? No.

What’s my future situation? Well, first of all, I’m the longest living person in the world born with my particular form of muscular dystrophy, and I’ve been told years ago that my IQ ranked in the top 10% in the United States. Not bad, considering that I only went to

school one hour a day, four days a week, through the 8th grade in my home.

This all sounds truly amazing and inspirational, doesn’t it? Well, I wish I could say yes, but I would be lying. As of now there will be no reward for accomplishing these two feats. Approximately a year and a half from now my insurance money will hit its cap. This policy, for the last 20 years, has paid for my personal attendants which, ultimately, keep me from going to a nursing home, where I will most certainly die in a few short months.

My country wastes more in a day than what it would cost to keep me alive for 25 years. It spends billions to kill people overseas, but it won’t spend pocket change to keep its own people alive. Thank you, Mr. Bush, for your help and concern. I’ll certainly think of you, too, come November.

There are, however, some politicians who do care. Senators Byron Dorgan and Kent Conrad, I’m lucky and thankful to say, are on my side. Along with these two, I also have some social workers, advocacy groups and, of course, Freedom Resources on my side, but time is running out for me. What I would like to see done by Medicaid and/or Home and Community Based Services is to take a page from my own insurance company, BC/BS.

When I first had to have attendants, my policy stated that I had to have licensed RN’s or LPN’s to work for me. In the next few years one of my “licensed” nurses and myself decided that anyone mature and responsible could do this job, hence extending my money and cap. I went to Senator Dorgan (congressman at the time) and told him of my situation. With his help, BC/BS agreed to allow me to hire anyone I wanted, licensed or unlicensed. All I had to do in return was sign a paper stating that I wouldn’t come back and sue them if something happened to me due to a mishap on the part of an unlicensed person. So, for the past 15 years I’ve had unlicensed people working for me, giving me probably two to three years on my cap. The result of this agreement has been wonderful. If every state would take a page from this book, it would save them a great deal of money and alleviate the misery and heartache of the people who would be pushed into a nursing home who wouldn’t have to be there. This plan is cost effective and it WORKS, trust me. Fifteen years can’t all be wrong.

Why do I sometimes wish I were the above tree, whale or insect? Because I would certainly have Tom Brokaw, Dan Rather and Peter Jennings flashing my dilemma all over the three major networks. Shows like 60 Minutes, 20/20, Dateline and 48 hours would quickly follow. Soon after all this publicity, many of this nation's elite would dig deep into their billfolds as if it was the Grand Canyon, and all of my troubles would be over. The axe wouldn't swing, I would be pushed back into the ocean, and I would be taken off of the Endangered Species List.

SB 2330 Work Group

By Chuck Stebbins

Here's another legislative update y'all may be interested in. SB 2330, the Money Follows the Person, work group has been meeting on a regular bases, and has actually made some progress, albeit the progress is in the area of why this particular piece of legislation won't work in North Dakota...gee, imagine that...nonetheless, it is movement. A little history of SB 2330. The language for the bill was sent to Senator Tim Mathern the night before the deadline...now, I'm not one to mention names, but I believe it was that Stebbins character over here who was responsible for getting that in...Anyway, it got to the senator, and in turn we ended up with the bill. It said, whatever it costs to be in a nursing home, that cost should follow you out into the community if you so choose.

We were kind of hoping it would go through without much interest, ya know, kind of sneak one in on em.. Hey, they do it to us all the time. But unfortunately it didn't happen that way. The original language would have made it a true "Money Follows the Person" bill, had it stayed the way it was introduced. What we ended up with was a bill that would not allow a person leaving the nursing home to use any more than the \$2400.00 that the Medicaid wavier for aged and disabled allowed anyway. So, the bill was essentially worthless. But, it did create a work group, which brought people to the table who need to get to the table: Aging Services, CIL's, Long Term Care, and others. So, that was a good thing, and still is a good thing, as we continue to meet to try and find solutions to improving the choices for people with disabilities and the elderly so we can stay in our own homes and avoid nursing home placement...cause ya know, "There's No Place Like Home"...right Pam?

The Wacky World of Peer Mentoring



Hello, for those who have not met me yet my name is Julie Dotzenrod, the new Peer Mentor Specialist here at Freedom Resource Center. I would like to take this opportunity to let everyone know how enthusiastic I am to be working at such an

exceptional organization. I look forward to getting to know everyone better.

Just to let you know a little about me, I am originally from Wyndmere, ND. This last spring I graduated from St. Cloud State University with a major in Community Psychology and a minor in Child and Family Studies. I lived in St. Cloud for four years going to school and was assistant manager at an after school program. I really enjoyed my job and education at St. Cloud, but it was time to move on to bigger and better things! I recently moved to Fargo to start graduate school at NDSU for school counseling and am fortunate to have found a job that allows me the opportunity to work with great people on such an imperative mission.

Since I started here I have discovered an issue of concern that I would like to share with you. In fact, perhaps you could be of service. The problem, I have discovered, is we have more people in need of mentors than there are mentors! Do you see the problem and need for concern? Therefore, I am asking, begging, pleading, however you want to phrase it, for your help finding mentors. I have already contacted a number of organizations in the community; however you may know someone or an agency that might need to be contacted. Please, refer them to me so that I can get this issue taken care of! Thank you, and I look forward to hearing from you. You can reach me at 800-450-0459 or email at julied@freedomrc.org.

Transition Corner:

What Would People Do?

By Amanda Krause, age 17

Two people who have inspired me, as a person with a disability and dealing with people who do not have one, are Rosa Parks and Martin Luther King. Sometimes, as we all know, it is really hard to keep a good attitude when faced with people who do not have a clue. Rosa Parks changed our whole country by sitting. Martin Luther King refused to get out of the faces of people who hated his color and made people deal with him, and those like him, peaceably. He kept his good attitude. Another person who inspires me is Jesus. Now, he made a few people uncomfortable, and they didn't know how to act or what to do around him...just like me in many ways.

When I go to my favorite hair salon to have my hair done I do not give up and not go because of the zillion steps in my way. I simply wait at the end of the steps for them to come and get me. You see, as Rosa Parks did, I sit. As she did, I do not get mad and start yelling (not that I don't want to). I just refuse to move. I know in my heart of hearts that when they get tired of doing that over and over they will be forced to think of accessibility in their building, and hopefully do something about it. I have a right to get my hair done. I have a right to shop. I like to do these things, so I will sit, and I will refuse to give up my spot. But I will do it in a peaceful manner and with a good attitude.

Now, keeping a good attitude like Martin Luther King did is hard. Let's face it, we probably have never faced the persecution like black people have in this country. But, we have had our fair share of injustice. When cities refuse to put in adequate parking for us to get around, or refuse to even abide by the ADA laws, we are being discriminated against. When I get really frustrated over this issue I have a fantasy I draw on for support. Just imagine what towns and cities would do if we had a silent "walk and roll?" We wouldn't have a silent march because not all of us can march, but we could walk and roll. I imagine thousands of us in one town or city. Really, W-W-P-D? (What would people do)...spray us with garden hoses, or think maybe they need to make changes?

Changing a few things is my mission in my community, including churches. I know many people with disabilities do not go to church because most churches are not accessible for us. They simply do not know how to act or what to do about us. Most churches claim that they

do not have the money to make changes in their building to accommodate us. This may be true, but I often want to say to those churches, "Have you thought of what our families go through to accommodate us? We know it is expensive. You are singing to the choir on that one." My mom is a single parent and has had to have everything done to our house. Having an accessible house is only a drop in the bucket of things that we needed. I have seen her work three jobs plus go to school full time. All she has is God to trust. So hearing from a church that they can't afford it is no excuse to me. According to Chuck Swindell, over 40% of Christ's ministry was based around people with disabilities and yet fewer than 5% of churches are accessible for us. That is sad.

I heard a girl, who also used a chair, say she hated it when church people would come up to her and with sympathy say, "I am praying for your healing." Most people don't know how to handle wheels. We all know that, but for some reason, people assume we are suffering and need a healing. I don't like the way I am treated sometimes. But giving up and not going to church is not going to help the problem. How else are they going to know that their accessible bathroom needs handrails, or that their wheelchair ramp is way too dangerous and not even legal? How can they change when they have no one to ask about it or, in my case, complain? The church I go to is built on a hill. In order for me to get downstairs to upstairs or vice versa I have to go outside and up and around the hill. The bathroom downstairs is not accessible so I have to go upstairs when there is youth group. My solution for this problem was not getting mad. I simply sit and ask leaders to take me to the bathroom each Wednesday. So each Wednesday we make the trek up the hill in rain, snow, sleet, or ice and back down again. I simply sit.

Whether we are dealing with common public or churches, I feel we need to let them know that we are part of the community. We live here, we shop here, we have dreams, we have lives to live here, and we go to church here. We are part of them. We are not, and we will not, just go away.

Freedom Resource Center and/or its Board of Directors do not necessarily endorse or support any of the views expressed within the personal testimonies within this newsletter, with the exception of those specifically so attributed.

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room, and second, we don't want your eyes glazing over when you're reading any portion of this newsletter. Why? Because we care gosh darnit, because we care! If you want to read the whole thing, you can go to www.kff.org, and follow the links. Following are some key points, or, at least I thought they were.

“Olmstead established two legal principles fundamental to health policy for persons with disabilities. The first is that the medically unjustifiable institutionalization of persons with disabilities who desire to live in the community violates Title II of the Americans with Disabilities Act (ADA), which applies to publicly-funded services. The second is that states have a legal obligation to affirmatively remedy such discriminatory practices through reasonable modifications to public programs and services.” In other words, fix it, so I can stay in my own home.

Because judicial intervention powers are carefully circumscribed (that means limit, or encircle) both by Olmstead and the ADA itself, the policy development and implementation processes gain critical importance in gauging progress toward community integration. In this regard, the past 5 years have witnessed considerable interest and movement, at both the federal and state levels of government.

Regarding this last statement, North Dakota has probably made the most progress in the “interest” department, but has set up an Olmstead Commission and has awarded a few grants to develop alternatives to nursing homes. Minnesota has no Olmstead Commission, but has made progress on the development of Home and Community Based Services in the past, so the state felt there was no need for one.

With that, we will leave you with what is currently going on in Georgia, five years post Olmstead.

Georgia's plan is remarkably faithful to Olmstead, and it is meant to be a continuing process, confronted on an annual basis. The Department of Human Resources is the lead agency, and the Office of Planning and Budget oversees the state's efforts to address Olmstead. The planning goals are the following: 1) transition those in institutions to community care; 2) divert people at risk in the community from institutions;

3) build system and provider capacity; and 4) gain commitment from the state to provide resources for the plan to go forward. The state focuses on getting people out of institutions, not just on making community care better. It provides allowances for housing and other necessary funding when transitioning individuals from institutions to the community. In the area of mental health, the state has tried to enhance the quality of the mental health services by using a general assessment tool to evaluate a person's ability to move into community care if they desire to move. The focus areas of the plan include: housing, identification and assessment, education and outreach, workforce development, transportation, assistive technology, and transition planning.

So, there ya have it, a short but oh so sweet synopsis of a very long report from the Kaiser Foundation. If Georgia is any indication of what has to happen before change can be made, North Dakota may want to pay particular attention, given our struggle to improve Home and Community Based Services.

**CHECK OUT THE NEWSLETTER
ON THE WEB AT
WWW.FREEDOMRC.ORG**

New Employee at Freedom

My name is Kami Davidson. I started working at Freedom Resource Center in April of this year as the Receptionist. I

have lived in Fargo for 13 years and have 3 sons. Dylin, 12, Devin, 6 and Tru, 5. It has always been my goal to work for a



company that makes a difference in people's lives, and I have definitely found that here at Freedom. I feel very blessed to work with such an amazing group of people, all dedicated to improving the lives of people with disabilities.

Ask Bob:

Dear Bob,

I'm 22 and I went out on a date with someone who is in a wheelchair. She's 21 and I would like to have sex with her. How do I approach her about having sex and how do we do it?

Jim

Dear Jim,

First of all - you both need to be comfortable with the situation. The best way to accomplish that is to talk about it. You don't seem to have any concerns about the wheelchair itself - so open up a dialogue about intimacy.

Dear Bob:

Women's public restrooms are usually equipped with one 'wheelchair' stall. (I imagine men's restrooms must have one also, though I don't think this question applies as much to men.) We've all been to events where there is a long line for the restroom, concerts, ballgames, etc. Typically, we use whichever stall opens up next. However, if a woman in a wheelchair needs to use the restroom, must she wait in line or is it assumed she is next in line for the 'wheelchair' stall? It seems reasonable to me that she wouldn't mind waiting and when she is close to the front of the line, then she is the next one for the wheelchair stall. But do women in wheelchairs expect to jump to the head of the line or wait in line with everyone else? I really don't know and don't want to offend anyone.

Anonymous in Minnesota.

Dear anonymous,

One can assume that the restroom would be full, I've not seen a women's restroom that hasn't been at events yet. I would think that the regular protocol would apply simply because of sheer numbers, unless of course it is an emergency. In that case, you may offend someone if you do not get to the head of the line. I would suggest that if a person with a disability cannot possibly wait, they should have the priority for the larger stall, and let the people know in front that the flood gates will burst if they cannot get to the only stall they can use.

President signs Executive Order in honor of 14th Anniversary of the ADA - Homeland Security - INDIVIDUALS WITH DISABILITIES IN EMERGENCY PREPAREDNESS

In honor of the upcoming fourteenth anniversary of the signing of the Americans with Disabilities Act, which is next Monday, July 26, 2004, the President met with people with disabilities, federal workers involved with homeland security, and Secretary Tom Ridge in the Oval Office today. The President signed an executive order regarding emergency preparedness for people with disabilities before traveling to the Northeastern Illinois Public Safety Training Academy in Glenview, Illinois where he made remarks on homeland security.

The President realizes that individuals with disabilities may require special plans during times of emergency and this Executive Order emphasizes the importance of implementing emergency preparedness plans that accommodate individuals with disabilities. The Executive Order also establishes an Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities that will help agencies and private individuals and organizations take into account the unique needs of individuals with disabilities in their emergency preparedness planning.

In February 2001, the President announced his New Freedom Initiative - a comprehensive program to promote the full participation of people with disabilities in all areas of society by increasing access to assistive and universally designed technologies, expanding educational and employment opportunities, and promoting increased access into daily community life. Today's meeting in the Oval Office reflects the President's ongoing commitment to ensure that Americans with disabilities are able to enjoy all the opportunities our Nation has to offer.

For more information on the President's New Freedom Initiative and a 2004 New Freedom Initiative progress report, go to <http://www.whitehouse.gov/infocus/newfreedom/>

Coming to a Theater Near You

The wonderful world of Universal Design. Plans are being made as we speak for a workshop, seminar, little get together, we're not quite sure what we want to call it yet. My personal choice was; Lessens in Universal Design In Order To Change The Way One Thinks About Building Something (LUDINOTCTWOTABS). But, it seems that was too long...well ladeedadada! Anyway, we're looking at early January. Stay tuned for more information in the next newsletter.

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Celebrating 15 years of Service

Freedom Resource Center for Independent Living, Inc is holding its Annual Meeting on September 23, 2004. The theme for this year's Annual Meeting is Empowerment. The keynote speaker is Jodee Bock, a North Dakota native and independent consultant in organizational management, with a specialization in human resources and motivation. The meeting will be held at the North Dakota State University Alumni Center, 1241 N University Dr., Fargo.

- 5:30 Punch Social
- 6:00 Dinner
- 7:00 Presentation
- 7:20 Key Note Speaker, Jodee Bock
- 8:00 Awards

Tickets will be sold in advance in the three offices, Fergus Falls, Jamestown, and Fargo, for \$6.00. Sorry, no refunds. Deadline for ticket sales is September 7th.

**We encourage everyone to come, including current and past consumers, employees, and board members.◆