

the Independent

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What to Expect in 2007

by Chuck Stebbins, systems change advocate

As you read this...and we hope that you do...the lame duck session will be well into the past, and the new Congress has taken up business. No better time to ask, "Now what?" What can we expect from the new powers that be on the likes of stem cell research, Medicaid, the ADA Restoration Act, and the fallout from the Deficit Reduction Act (DRA)? Obviously we cannot know for sure what to expect, but we can strive to point out the importance of doing it right. Because at the very least, every one of the issues mentioned will have some kind of impact on the disability community.

On November 7th things changed a bit with one of the world's largest democracies. The Democrats now control both the Senate and the House. Will the tax cuts will go away, as well as the threat to the lower and middle class to pick up the tab? Will Section 8 housing vouchers be available

to everyone who needs one? We hope that Medicaid will be funded so people who need it will have it; and we can assume that we have a little breathing room to work on improving the lives of people with disabilities. However, the new "pay as you go" budget plan they are talking about may hold down any new spending.

The National Council on Independent Living (NCIL) says the President's 2007 HUD budget will weaken housing and community programs serving people with disabilities.

The President's 2007 budget request represents a 1.8% total decrease in the HUD budget, and specifically:

- Housing for Persons with Disabilities (Section 811) program is cut 50%.
- Tenant Based Rental Assistance (Vouchers) received a small increase, but the President and others have been hostile to the program,

attempting to severely cut it in the past. NCIL believes that these vouchers offer the most integrated housing choices for people with disabilities.

- Funding for Fair Housing enforcement is cut 2%, despite a recent study showing a high level of discrimination against persons with disabilities.
- USDA Rural Rental assistance, important for many people with disabilities who also face transportation challenges in rural areas, is cut 26%.
- The Community Development Fund, which often funds housing and accessibility modifications for low-income persons, has been cut 37%.

Recommendation(s): Prevent funding cuts in HUD programs, while increasing funds

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What's Wrong with this Picture?

Think Skinny!

What is the sense of putting
in a curb cut if you block
half of it with a huge pole?



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for Housing Choice Vouchers and Fair Housing Enforcement.

On the issue of access to health care, Medicaid continues to be a necessary program that gives people health care who would otherwise not be able to afford it. The Medicaid Commission established in 2005 has recently released a "chairman's mark" ...designed to "promote Medicaid's long-term fiscal sustainability, while emphasizing quality of care." As I read a little further I discovered that that means the Commission wants to give more flexibility to the states to deal with Medicaid.

Now this could go very badly, or it could go very well in 2007. It depends on where the priorities are for the state. For example; North Dakota is still an institutionally biased state when it comes to putting more money into the community-based systems, so unless otherwise changed, 90% of the Medicaid dollars would continue to go to the nursing homes. Minnesota however, has invested more and more in their home care system over the years that the dollars are starting to shift more toward in-home care. It is a better use of tax payer money, plus it will yield the state more money from the feds in the long run, because incentives have

been created to move states more toward home based systems.

The ADA restoration Act will be re-introduced in the 110th congress with the same comprehensive legislative recommendations for restoring civil rights protections for children and adults with physical, mental, cognitive and developmental disabilities that have been significantly weakened by the Supreme Court over the 16 year life of the ADA.

Freedom legislative priorities include, but are not limited to:

- **EMPLOYMENT**
We support efforts that will explore new solutions to the under utilization of people with disabilities in the work place. We will work to identify and remove all employment related barriers.
- **HOUSING**
We support all efforts that will increase accessible/affordable housing for people with disabilities in the community.
- **HOME AND COMMUNITY BASED SERVICES**
We support all efforts to provide services for people

with disabilities in the most integrated community setting possible.

- **EDUCATION**
We support a free and appropriate education for all persons with disabilities.
- **ACCESS TO MEDICAL TREATMENT**
Freedom Resource Center supports the availability of appropriate healthcare for all citizens, regardless of their income, age, or condition.

So, there you have it, a little taste of things to come. Not all, of course, but some near and dear to our heart here at Freedom. It looks to be a banner year for debate around issues that will profoundly affect the disability community. So get on somebody's bandwagon to help with the work. Even with the new Congress and state legislatures we have to be vigilant, because there is no guarantee that with change there will come prosperity and all the things on that wish list.

If you want more specifics on anything, or want to know what you can do to help, please call.

Happy New Year! ■

From Where I Sit

by Nate Aalgaard, executive director

In this issue of *the Independent*, we are trying to do something a little bit different. We are exploring some of the issues of disability in popular culture. What we are finding is that there are quite a few different places where you can see either actual people with disabilities, or a fairly accurate portrayal of their lives. This is progress. Because if you look back at historical portrayals of people with disabilities, you see a very negative legacy.

One interesting and fairly recent phenomena is the celebrity activist with a particular disability. Think about the impact that Christopher Reeve has had on spinal cord injury. As the most famous disabled person, and the most disabled famous person, he held a huge amount of power and influence simply by being who he was. And then there's Michael J. Fox, of *Spin City* and *Back to the Future* fame. He has put the issues of Parkinson's disease and stem cell research on the front page.

Many times, having a famous celebrity spokesperson also brings controversy, as it has for both Reeve and Fox. The Jerry Lewis Labor Day Telethon started out fairly small. As it grew, so did protests around the country by people with disabilities regarding the type of image that Lewis was portraying. They hated the "Jerry's kids" label, because they were neither kids, nor his. They objected to the emotional, orchestrated appeals, which they called pity. Eventually the protests died down, but the Muscular Dystrophy Association did change the telethon and the language somewhat. That's not to say that everybody's happy with it.

In my years working in the disability field, I have come to the realization that many people are willing to give freely of their time and money to help a cause. That's one of the greatest things about our country—the generous nature of our people. Sometimes organizations make that cause a sort of charitable event to help alleviate the suffering of a particular group. People contribute, because their hearts are in the right place. The fact is, this works. Money is raised, budgets are balanced, and projects are undertaken by well-meaning organizations.

But when you start talking about disability in terms of civil rights, you get a different response. People aren't going to open up their wallets and give you money because you're fighting some business that's not accessible. They're not going to put on special events so that you can hire lawyers to fight for employment rights.

What a lot of us want to see is a situation where disability is a normal experience. We'd rather not have it be seen as something that needs charitable support. We just want to live our lives like everybody else. The problem right now is that the environment (the system) is not working for us. We want to change that so that somebody has the same chance at a good job no matter if they have a disability or not; or has an equal opportunity to participate fully in the life of their community, disability or not; or even the chance to be elected



Nate Aalgaard, executive director

to some public office, no matter if they campaign on foot, on wheels, or with a service animal in tow.

The media is a tremendously powerful force in shaping public opinion. I would encourage people to continue to challenge inaccurate media portrayals by sending letters to news outlets and the producers and advertisers of various programs that are offensive. Write a letter to your local newspaper explaining what's wrong with a particular story or show. I also encourage people with disabilities to get out in the community and get involved. That's the only way people are going to learn what we can do and how much value there is in eliminating some of those environmental barriers that are holding us back. ■

Disability in Popular Culture Links

List of Films with disability related plots.

www.disabilityfilms.co.uk/categories.htm

Information on disability in popular culture

www.disabilityhistory.org/dwa/edge/curriculum/culture.htm

Discussion on People with Disabilities in the Public Eye

www.thegimpparade.blogspot.com/

Celebrity activists raise awareness and big money

by Nate Aalgaard, executive director

This past election, Michael J. Fox was out front in the Missouri U.S. Senate race campaigning for Claire McCaskill in her attempt to unseat incumbent Republican Jim Talent. The reason: support for stem cell research. In a television ad that eventually received far more in additional "news" coverage, he told Missouri voters that the saying "all politics is local" may not always be the case. He stated that they had the opportunity to make a bigger decision on behalf of millions of Americans like him. He talked about hope for people, while being shown visibly in the grip of involuntary movements that are part of living with Parkinson's disease.

The additional coverage of this state race came from media outlets nationwide, after Rush Limbaugh, the

biggest name in talk radio, decided to take issue with Fox's appearance in the ad. He accused Fox of exaggerating his movements for added effect. There was even video of Limbaugh mocking Fox, which appeared on many other cable and news programs.

Did Fox's injection of celebrity into a tight U.S. Senate race help determine the outcome? Did Rush Limbaugh's attack help, or hurt the Republican incumbent's campaign? Who knows. One thing is sure though. The Missouri Senate race in particular and stem cell research in general got more exposure that they otherwise would have without a famous spokesperson getting into the fray.

And Fox's cause? According to its website, to date, The Michael J. Fox Foundation for Parkinson's Research has funded over \$86 million in research, either directly or through partnerships. A recent fund raising gala held right after election day raised \$5.7 million for Parkinson's research. It was highlighted by such celebrities as Lonnie and Muhammad Ali, Cheryl and David Einhorn, Holly Andersen and Douglas Hirsch, and Helen and Martin Scorsese. The nearly 1,000 guests included Denis Leary, Susan Sarandon,

and Donny Deutsch; along with performances by rock icons Sheryl Crow, Rob Thomas, Elvis Costello, and Axl Rose.

Fox is doing for Parkinson's what Christopher Reeve has done for spinal cord injury (SCI). After his injury in 1995, Reeve started a foundation in his name to fund research into a cure for SCI. To date, that foundation has spent over \$20 million on research, along with funding quality of life and health promotion grants.

Celebrity not only comes with added awareness and funding, it can also bring controversy. Similar to the issue Fox faced with Limbaugh, Reeve faced protests from some disability activists over his initial insistence on "cure" over the more immediate issues of access and civil rights. One disability activist in the Twin Cities said that when Reeve was to be at the Courage Center to accept an award, she planned to be out front with a sign saying, "we've got the *criptonite*." A clever play on words, but in the end the Christopher Reeve Foundation did change its focus a bit. No matter the effect of the protests for either Fox or Reeve's causes, there is still a lot more exposure, and money, for their issues. ■

Stem cell research has mutated into a legislative hot button that has caused a lot of concern and fear for some, and a whole lot of hope for some in the disability community. This issue will directly impact the disability community on physical, political, ethical, and moral levels.

California and New Jersey have passed legislation to allow for embryonic stem cell research. Other states are considering such legislation. On the federal level, there were eight pieces of legislation regarding stem cell research in the 109th congress. We can expect at least that number when the 110th convenes this month.

Modern children and family movies that show disability often continue to show disabilities in ways that are often inconstant with independent living philosophy. These movies show disability, not as a natural part of life, but rather show people with disabilities as special and inspiring.

Examples of this include Forest in Forest Gump, Nemo in Finding Nemo, and Sam in I am Sam. While these movies can be and often are entertaining, they become harmful to us when we began to view all people with disabilities as special or inspiring. Doing that creates unrealistic expectations for people who are trying to be integrated parts of the community.

As we spend our entertainment dollars, it is important that we seek out movies for our children that portray disabilities in realistic ways. Look for movies in which characters' disabilities are not the primary forces of their character. Seek out characters with disabilities that are villains and heroes and everything in between.

Children with Disabilities and the Media

by Stefanie Gaulrapp

Throughout the years, movies and T.V shows, mainly those produced for young children, are including more characters with disabilities. Living with a disability has become a part of our everyday life. Disability experts say it's important for children with disabilities to see themselves reflected in TV and movie characters because it shows them that they're not alone in the world.

Seeing individuals with disabilities gives viewers someone out of the ordinary to relate to, and may help people affected by a disability explain their disabilities to others. Being exposed to characters with disabilities is also helpful to nondisabled kids, who might not know anyone with a disability. It can show them that kids with disabilities are just like everyone else, and this would serve as a bridge for communication between individuals who are disabled and non-disabled.

Watching a disabled character gives a disabled child representation. It is proof that they can live a life that is enjoyable and pleasing. In the year 2000, the Disney Channel released "Miracle in Lane 2." This is a movie that positively describes a character with a disability. Justin Yoder, 13, who is played by Frankie Muniz of "Malcolm in the Middle," uses a wheelchair



In "Miracle in Lane 2," Justin Yoder celebrates his victory with his crew members. Photo courtesy of the Disney Channel.

because of spina bifida and dreams of winning trophies like his older able-bodied brother. Justin's confidence in himself helps his dream come true when he takes part in a soapbox derby. His family is worried, but Justin does whatever it takes to make his dream a reality and wins the race. This movie is based on a true story and sends out a message that people with disabilities have the strength to accomplish anything. All it takes is having faith in themselves and finding others who believe in them.

When looking at the results of what both TV and movies do to influence children's views, it would be nice to see more shows with a disabled person in them. This would make it easier for kids to identify with someone who has a disability. Currently there are a low number of disabled images portrayed on television, and the roles they play aren't always positive. How often does a viewer see a main character with a disability? For some reason when someone thinks of a movie or TV show involving someone with a disability, the viewer remembers that show in a negative manner. According to Nick Morales of the advocacy group Arizona Bridge to Independent Living, most physically disabled people wish to live as independently as possible, and would like to be treated as people first, disabled second. And, they don't want to be thought of as "unable."

Viewers might be used to the able-bodied character. However, using actual people with disabilities in the media would bring a better understanding to the outside world, especially children who need to understand other kids with disabilities live very fulfilling and successful lives. ■

Information

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Alternate formats available upon request.

Editorial Board: Nate Aalgaard, Scott Burlingame, Deane Feland, Stefanie Gaulrapp, DeAnn LaFond, Chuck Stebbins

Nip/Tuck's Spin on Disability

by Scott Burlingame, assistant program director

This article is not for the children, neither is the show *Nip/Tuck*. *Nip/Tuck* (FX network) is one of the most popular shows on cable television. The show follows the lives of two Miami plastic surgeons, Sean McNamara (Dylan Walsh) and Christian Troy (Julian McMahon), and their efforts to make their clients look perfect, and their personal struggles with trying to be perfect themselves. This premise has led to some of TV's best and most blunt and realistic portrayals of disability issues and the lives of people with disabilities.

During the current and fourth season, there have been some amazing exchanges regarding disability issues on the show. This started with Dr. McNamara and his wife, Julia, who find out they are going to have a son born with ectrodactyly, commonly known as lobster claw syndrome. This realization leads to three different scenarios that are very realistic for parents of children with disabilities.

First, the parents are shown having to decide between having the baby or aborting (they choose to have it). Then the family must decide to let the baby live as he was born or to put him through painful and invasive surgery and therapy to "fix" his hands. They are finally shown struggling to find help for the baby from someone who understands his special needs.

In this process they hire Marlo, who is a little person. Marlo introduces the McNamara's to what we call Independent Living and the concept of disability as a civil rights issue. He encourages the family to let the baby live as he is, and not put him through the painful surgery at such a young age.

The character Marlo is also very interesting. In a media world where people with disabilities are often viewed as helpless and to be pitied; he is shown to be employed as a night nurse, he is educated in Art History, and he is sexual (including having an extramarital affair with Julia).

In the end, the theme of this storyline appears to be that even in a world where plastic surgery to make people look perfect is the norm, disability is a natural part of life. While the program is often vulgar and distasteful in its description of life with a disability, in the end, the people and their characters obscure the disability. ■

Little People BIG WORLD

by DeAnn LaFond, office coordinator



Little People BIG WORLD is a reality show that features the Roloff family. TLC has had positive rating for the show and it will be starting its second season this fall. This show portrays little people in a positive way and avoids any stereotypical light. It shows how a family of six deals with everyday life from a little people prospective.

The family consists of six members. The father, Matt, has diastrophic dysplasia, a condition that affects bone and joint structure and leads to broad, short fingers. He spent most of his childhood in hospitals. Matt is a successful salesman, entrepreneur, and advocate for the rights of little people. The mother, Amy, has achondroplasia, a genetic condition that results in short arms and legs. Amy works two jobs and manages the family and the farm. Zach and Jeremy are twins. Zach has achondroplasia while Jeremy is average height. The boys are 16 years old. Molly is average

height and is the only girl of four siblings. She is 13 years old. And last but not least, Jacob is nine years old and is of average height (already taller than his parents).

The Roloff family has a 34-acre farm in Oregon. The farm includes a complete Western town, a pirate ship on a lake, a three-story tree house and a medieval castle. Matt has many ideas and pursues them to make a living. He has published a book, and created a business that focuses on adaptive equipment for little people. Amy works two part time jobs and manages her family. The boys are involved with school and sports and just being kids. Molly also is in sports and school and gets caught up in a lot of the mischief that her brothers get into. Little People Big World shows how people with disabilities can live, work, and have the same problems that everyone else has. It shows everyday happenings from cooking, cleaning, doing homework, working jobs, and going on vacations. The program is on TLC, Saturdays at 7:00 pm Central Time. ■

Profiles in Advocacy: Larry Chial



Tee for One

by Larry Chial, board member

Until about five years ago, I would have been considered an "avid" golfer. That is, if your definition for "avid" is playing golf three or more times a week. I haven't played since then as I am not able to stand and walk as a result of the progression of my multiple sclerosis. For a few years, I have been aware of golf cars that are designed to allow individuals with mobility impairments to be able to play golf. This past summer, I did some additional research on-line regarding these products. When I felt that I knew enough about a particular car that would

meet the golf mobility needs of a significant number of individuals, I decided to formulate a plan to have one or more of these cars available at a golf course in Fargo.

In order to accomplish some things, it helps to know the right person to contact and also be able to educate them about your mission. I've known Matt Cook, the golf professional at Rose Creek golf course for many years. I called Matt and discussed my goal of having the accessible golf cars available at their course. He was only slightly familiar with the SoloRider golf car. I reviewed its capabilities with him and he was definitely interested in the concept of allowing more individuals to play golf. Matt recommended that we schedule a meeting with Jim Larson. Jim is the finance manager for the Fargo Parks Department.

The three of us met and discussed the features and benefits of the SoloRider golf car. The SoloRider is designed for one rider, it has hand controls, a special swivel seat and slightly larger tires than a regular golf car. Oversized tires provide the ability to drive the car on the greens, up to tee boxes, and into the sand traps if necessary without causing any damages. The car costs about 50% more than a traditional golf car. Jim was also excited about the concept and agreed to work with Matt to include one or two of the cars in next year's budget.

At the end of the golf season, Matt hosted a meeting of area golf professionals and course supervisors. The program for the meeting was a presentation by Victor Romandine – Regional Sales Manager for SoloRider, Inc. He drove up from Chicago and brought a golf car along for demonstration purposes. Victor answered many questions and I think those in attendance agreed that the accessible golf car would provide many benefits with few problems.

At this time, the review of a competitive product is also going to be conducted. It looks like there will definitely be one or more of these cars available at the Rose Creek golf course when the season begins next spring. ■

Q: Is dwarfism considered a disability?

A: Opinions vary within the dwarf community. Certainly a number of short-stature people could be considered disabled as a result of conditions, mainly orthopedic, related to their type of dwarfism. In addition, access issues and problems exist even for healthy LPs. Consider, for example, the simple fact that most achondroplastic adults cannot reach an automated teller machine. Dwarfism is a recognized condition under the Americans with Disabilities Act. Information on the ADA is also available directly from the US Department of Justice, which administers the law.

Q/A from Matt Roloff on the following website.
[Http://tlc.discovery.com/fansites/pbw](http://tlc.discovery.com/fansites/pbw)





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RETURN SERVICE REQUESTED

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.

Up Coming Events...

State of the Cities - February 13, 2007 Ramada Plaza Suites, Fargo 7:30 - 9:00 am.

For more info - Kelli @ 218-233-4347 ext 11



Save the Date: Annual Windmill Project Parent Retreat 2007! March 30 and 31, Holiday Inn, Alexandria MN. For more information contact Gail at gail@rea-alp.com, the website www.windmillproject.org or 320-763-9228.



Assistive Technology Expo - April 5 Ramada Plaza Suites Fargo. For more info call Jeannie Krull 800-895-4728.



Want to learn how to become more involved in the community?

Freedom Resource Center is holding two **Becoming a Leader in the Advocacy Movement Sessions**.

A training in Jamestown, ND will start February 17th and meet every other Saturday for three sessions.

A training in Moorhead, MN is going to be held but the start date will be announced at a latter date.

If interested in attending these sessions or have questions, please call Scott at Freedom 701-478-0459 or 800-450-0459.