

# **The People First Connection**

**The Voice of Self-Advocacy in Oregon  
Published by Self-Advocates As Leaders**

---

---



## **Don't Shut Me Out!**

**Amelia Abel  
Eugene**

**My name is Amelia Abel. I am 15 years old. I go to Sheldon High School in Eugene. I am an honor student. I am writing because I believe that we should treat each other the way that we want others to treat us.**

**I have a disability called Down syndrome. Sometimes it is hard having a disability. I look different from other people, and sometimes I feel embarrassed that people might talk to each other about me.**

**Kids with disabilities sometimes are sad and uncomfortable when they are with other kids. We feel embarrassed or shy because we are different. When I walk down**

**the hallways at school, kids don't notice me, they don't say anything to me, and they will never know me.**

**At school, regular kids exclude me from their activities. I want to participate at school with regular kids and be included. I want to feel a part of the school. I want to go to sports and activities at the school. I want to join groups and socialize with regular kids.**

**I just feel like I am a regular kid.**

**I am special in many ways, and I am just like other kids in many ways. I like math. I like to read. I try my hardest to participate in the regular school. This year I took choir and dance. I liked being with regular kids; I wish I**

# Don't Shut Me Out!

could have more time with them so we could get to know each other.

People with disabilities just want to be treated like regular people. Sometimes people look at me funny or avoid talking to me. They treat me differently than other kids. When people do this, I feel lonely and isolated. I like it when people talk to me and really listen to what I have to say. Then I feel accepted.

When I talk about feeling excluded, students at school do not believe what I say. They don't listen to my words. They just look at me and see my disability. They don't see that I am a regular person.

I worry that this will never change.

It is like regular kids are living on the inside of the world. I want to be on the inside too. I don't want to live on the outside of the world my whole life.

I know that I have a disability and am different from other people. I am OK with that. I think that other people do not like me or are uncomfortable with me because I have Down syndrome. People seem to ignore me. It is like they hang out with their friends inside a little bubble and do not make new friends.

We are taught at school to treat people with respect and dignity, but people in the world do not treat people with disabilities very well. I wish people would make an effort to make friends with people with different disabilities. People should reach out of their bubble and get to know us for who we are.

*Amelia Abel published this article as a guest editorial in her local newspaper.*



# April Showers Fall

Judy Cunio  
Oregon Council on  
Developmental Disabilities

April was quite a month for people with disabilities. And there were many opportunities for our voices to be heard on different issues.

The first event was held on April 4, by the Help America Vote Act Committee. They held a Vendor Fair at the Oregon State Capitol. They brought in different types of voting machines for people to try out. There were about 200 people with disabilities who tried them and got to vote on which machines they liked and disliked. And, like almost everything else, one size does not fit all.

The next big event was on Monday April 18 when there were several activities going on at the Capitol all day. It was a combination of Lobby Day and Developmental Disabilities Awareness Day.

The day began with a hearing on a bill called the Respectful Language Bill. If the bill is passed, it will mean that from this point on, when new legislation is written, the language will have to put the person before the disability.

For example, instead of saying "disabled person", the legislation would say "person with a disability." Or, instead of "cerebral palsy victim," it would say "person with cerebral palsy."

We need to respect all people for who they are, not for what disabilities they have. Because, when you really think about it, doesn't everyone have some sort of disability?

Following the hearing, there was a short training session on how to advocate to your legislator. After the training, people went to see the Legislature at work. Some people went to the House side and some people went to the Senate side.

Then people were sent out to go and talk with their own legislators about House Bill 3047, the Respectful Language Bill.

## **April Showers (cont.)**

**At noon, everyone gathered at the steps of the Capitol to celebrate DD Awareness. Governor Kulongoski signed a proclamation.**

**He also unveiled this year's DD Awareness poster. State Representative Billy Dalto received an award for all of the work he has done on behalf of DD issues.**

**On April 27, Self-Advocates As Leaders (SAAL) hosted a reception at the National Conference of State DD Directors which was held in Portland. More than a dozen people who are self-advocates met and welcomed the directors to Oregon. There was music and food, and an opportunity to get to know each other. Everyone seemed to have a great time.**

**The band that played was made up of a group of self-advocates from Corvallis.**

**Self-Advocates in Oregon are on the move!**

**WHY NOT GET ON BOARD?**

## **Upside Down**

**Heather Halko  
Hillsboro**

**I graduated from high school in 2003. Now that I am 21, and out of the school system, my whole world has basically been turned upside down and inside out.**

**If it weren't for my service brokerage, SDRI, I don't know where I would be today. I have a personal agent. He is trying to help me with all of the issues I have. Issues like what to do with the rest of my life and how to do it. If it were not for him and his help I would feel like I am walking in the dark without any guidance whatsoever.**

**I still don't know how the system really works but my agent and I are trying to find out as we go along.**

**I am able to go out into the community and I have a job. I am also able to go to the YMCA. I am in a play. I go swimming; I do art and just talk to people around me and have fun.**

# Upside Down (cont.)

When I am at work, I do some data entry. I take pictures with a digital camera. I get on the computer and rotate the pictures and I do other jobs that I know I can do.

In the future, I would like to see my service dollars helping me pay for attendant care in housing. I would also like a better, more permanent, job than the one I now have.

If my service dollars were taken away for any reason at all, I would be stuck at home in my room all day long and it would be extremely boring after a while.

Hopefully, after receiving my story, the legislators and other people who read this will know and understand how serious my issues really are and not cut funding for important programs.

=====  
*All articles in  
The People First Connection  
are subject to editing for spelling,  
grammar and content.*  
=====

# Home ERC

Patrick Glass  
Hillsboro

My name is Patrick and I go to a school called Village Home Education Resource Center. Village Home is unlike other schools because it's for home-schoolers. It is my favorite school so far. I like it because my mom works there as a field trip coordinator and a classroom assistant and I'm always right by her.

Village Home rents space in a church.

When I come to Village Home on Mondays, I always get a copy of the weekly newsletter. The newsletter has announcements, field trip info, sports updates, book reviews, info on class mates, TV show reviews and comic reviews. I usually hang out at the kitchen, especially when they give away food. I also like the teen room because you can play board games in there.

The kids that come to Home Village are nice. Most of the kids are typical home-schoolers. There are only some kids that have disabilities, but everyone

# Home Village (cont.)

treats me very nice. I've made four friends there. One of my friends, Connor, is a nice kid. He works on the newsletter.

Another one of my friends is Liz. (NOT MY GIRLFRIEND, OK?) She has an interest in Anime and video games.

I have the same teacher for both of my classes. What I really like in class is when Mr. Owens gives out candy, yah! This is only on rare occasions.

Next semester, I plan to add two more classes. I am going to take a web design class and an ancient history class.

Well, I hope everyone liked this essay and I hope you will come to visit Village Home.

=====

*“Advocate as if your life depended on it, because it does.”*

*Justin Dart, Jr.*

=====

# Day-to-Day Survival

Ann Blackburn  
Beaverton

I receive services through the Aging and Disabilities Office and not the Developmental Disabilities system. I know first hand how crucial these services are.

I am an adult with cerebral palsy and I used to own my own home. I rely on services funded by the state for my day-to-day survival, such as getting out of bed, bathing and eating.

I live a very full and active life but without state funded services I wouldn't be able to run my business, be an active contributing member of society or, for that matter, have control of my own life.

I have had my own apartment since I was 19 years old. I lived in England and, when I moved to the Portland area, I bought a condo in downtown Beaverton. I was very proud of my home and the fact that I was able to live in my own place. Yes, I had someone who came to help me with my daily needs. Being a

## **Day-to-Day Survival (cont.)**

property owner gave me a sense of pride and security.

The problem when I lived by myself was the fact that in-home care was totally my responsibility and that meant finding people, hiring and scheduling all fell on me and my mother. This was very time-consuming and stressful, especially when, in May of 2004, in a space of two weeks, both of my caregivers quit. That left me back at square one. It was the last straw. I had had enough.

At that point, I looked at other options. I had heard about a kind of assisted living where I would have my own apartment in a building with staff. This differs from other arrangements in that I would be responsible for scheduling the help I needed. I liked that fact that it would be up to me to decide what help I needed and when I needed it.

I was very conflicted before I moved. On the one hand, I was tired of the ongoing stress. The idea of being able to get help whenever I needed it was very

appealing. On the other hand, it was very scary and heartbreaking having to leave a home that I loved and had made my own. Thinking of moving into a totally strange and new situation made me cry for two days straight.

But, I did move and it is fine. Living here feels completely different for many reasons. One of the main differences is that I don't feel like I have the privacy I had in my own home. But, as it turns out, the move was a good one. For the first time in my life, I am able to have the kind of flexibility that most people take for granted. I am able to do some things I always wanted to do, but couldn't because of constraints with my in-home help.

---

## **Freedom**

Charlene Dean  
Tillamook

I like my brokerage. I have met a lot of nice people. I recently toured the capitol in Salem and had a really nice time.

I appreciate the Dial-A-Ride. It gives me freedom I would not otherwise have.

# I GOT IT!

Barb Kragrud  
Beaverton

After we had auditions for *Carousel* we waited for several weeks before finding out which parts we got. It was very hard for me to wait. Finally the cast list was posted in the choir room, and we all gathered around to look at it. I waited in the back until everyone else had looked. Nobody said anything to spoil the surprise, and when I looked, there was my name next to "Julie Jordan." I had the lead in *Carousel!* A part I had dreamed about for a long, long time.

The hardest scene for me was the one in which Billy killed himself with a knife. We were coming back from the clambake. The audience knew what had happened, but I was in the back of the crowd. When I heard somebody say, "It's Bigelow," I said, "Billy?" and began running and pushing people out of my way to get to his side.

When I said his name, I pretended to have a lump in my throat, and when I was really into the part, I did in fact have a lump in my throat. I said his

name in a soft stage voice, just loud enough for the audience to hear so that his name would sound like a question. I was afraid something bad had happened, but at that moment I didn't know what.

Two more times I said Billy's name, each time in a different way to show my growing realization that something terrible had happened. The second time was more intense, but when I said his name the third time, my voice had to tell the audience that I knew the man I loved was dying. So I didn't speak words; I cried, and the words came through my sobs. As the scene ended, Billy died in my arms, and, stroking his hair, I said, "Sleep Billy ...Sleep peaceful now."

One of the reasons the scene was so difficult for me was that I had to cry. I was holding Billy like a baby when he said, "Little Julie." I thought of something very sad, such as someone I knew who was dying or something someone said that really hurt my feelings. Within a few moments, tears would come to my eyes.

And that's when the magic happened. The tears that began when I thought of something else

# **I Got It!**

## **(cont.)**

suddenly turned me into Julie Jordan, and when Billy breathed his last word, “Julie,” and I said, “Oh, Billy,” he really was Billy, and Greg and Barb had disappeared.

=====

# **Chicken Soup**

Cynthia O’Neal  
Corbett

I smell something. Chicken soup. I am five-and-a-half, and Mom’s in the kitchen cutting up carrots and celery, onions and garlic.

I’m in the playroom with my sister because Mom doesn’t want any hot soup spilling on her babies. I hear her knife on the chopping board, but it’s the smell that makes it hard to concentrate on our game.

My mom made a lot of good things: vegetable soup with potatoes and those letters and lots of meat; spaghetti, chocolate cake. But whenever there was chicken in the pot, for soup or

dumplings or gumbo, we couldn’t think of anything but dinner.

I’m 51 now, but whenever I smell chicken soup, I’m five-and-a-half, and Mom’s in the kitchen, cooking something good.

=====

# **Favorites**

Luis Micheal Ross  
McMinnville

I like key chains. I cut the ends out and then I put it in the key chain machine. I like to do my laundry. I clean my house and then I work my way down to the laundry. I also cut the grass.

During the holidays, my sister comes to visit me. We watch movies, except on Christmas when we have a tree and open presents. My favorite food is tacos. I like the hard shell tacos with beef.

I go for walks. I go down to Dutch Brothers for decaf coffee. I do this at least once a week.

I have a girlfriend named Danielle. She and I go out for walks together. Sometimes we watch movies together. These things are all my favorites.

# **SAAL Would Like to Come to Town!**

**Self Advocates As Leaders  
would like to host training in  
your area.**

**For information and/or to  
schedule training, contact  
MARCIE at 1-888-589-1664 or  
email [alvarezm@pdx.edu](mailto:alvarezm@pdx.edu)**

**You may visit our website at:**

**[www.asksaal.org](http://www.asksaal.org)**



## **Self Respect**

**Cyndi Pendry  
McMinnville**

**Once upon a time I was healthy. I was a physical therapist working with burn patients. Later I moved to Oregon and bought a big boarding kennel, where I boarded and trained dogs. But I got sick. As a physical therapist I worked with lots of blood and picked up the Hepatitis C virus. On top of the world one moment, and so sick I could not care for myself the next. I lost everything, especially my self-esteem.**

**I had to rebuild my whole life. I had never realized how different people can be. But, on the one hand, there were councilors working for Yamhill County who became my lifeline back into the working world. But my greatest pain came from people who had the misconception that I might have brought all this disaster upon myself, that it might spread to them, or others who said, “She lies, she was never what she claims to be.”**

**Of course this happens, and it hurts when it does. But with the**

## **Self-Esteem (cont.)**

help of my friends, I got through it. I am finally working and gaining respect again. Yet, everyday I watch people come through Vocational Rehabilitation, some worse off than I was, some not so bad, yet they are trying to regain position, trust, respect and a sense of truth. When you in the community feel inclined to judge someone like me by the events in my life, ask yourself one question: could you have overcome what I have had to overcome? Could you climb out of a hole that deep without a hand being extended to help?

I have great pride in what I have been through. If you really look at me you will see that I shine with a new found knowledge. All I have gone through changed me for the better. I am grateful that I went through it and sad for those who can't see the truth in me.

I didn't need disability to teach me to respect all people. My family taught me that. But now I have a far deeper pride in myself.

## **A Big Challenge**

Nancy Jameson  
Portland

I played the part of Mabel in *Pirates of Penzance*. That was a very big challenge for me. I was very nervous, especially near the end when I had to sing a very long song with lots of high notes.

My lips started to flutter as though they were the wings of a butterfly trying to escape a scary place. But they were stuck to my face, so I had no choice but to breathe, relax, and let the butterfly go. Before I knew it, I had disappeared. I looked at the directors and their faces told me that the butterfly was free once again.

I loved wearing my white dress with the pink ruffles and my hat with the bouquet of flowers on top. When I opened my pink umbrella, I felt like a Princess who, at the touch of a pirate's heart, had just emerged from her cocoon.

=====  
*Email stories to us at*  
[mtbclarion@comcast.net](mailto:mtbclarion@comcast.net)