

The People First **Connection**

The Voice of Self Advocacy in Oregon
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Outside the Box

Stephanie Thomas
Houston, Texas

After these many difficult and exciting years engrossed in disability advocacy, there are two changes that I deeply want to see. The obvious one is for people with disabilities to be fully included in society. The other is to see people with disabilities ourselves actually feel we are fully entitled to be part of that society.

The past couple of decades have seen a lot of change, but there is still a very long way to go. As society's negative messages about disability continue to bombard us, we tend to internalize them and feel there is something wrong with us - a self-fulfilling downward spiral we must break. I've met too many

people who think they are the problem – feeling they take up too much room, are too much trouble, that they don't deserve a good life.

Way too often we allow ourselves to accept the unacceptable. Why is something considered a “public” place or service – except that it won't let YOU inside or won't serve YOU? Like a restaurant that won't serve someone with a service animal, or a hotel that “loses” your reservation when they find out you have significant physical disabilities or speech impairment. It isn't okay. Why is it okay that thousands of us are expected to live our lives out in a nursing home, when people just like us live in their own homes? It isn't okay.

I've been called an outside agitator, a troublemaker, but did I make the trouble? I didn't build an inaccessible building, didn't vote for a discriminatory policy. What I did was to decide to stop cooperating with the

Outside the Box (cont.)

charade that everything is okay the way it is.

Let's face it; if we don't think we belong, that we deserve a place at the table, why should anyone else? We can only find the motivation and do what it takes to make that happen, when we truly believe we belong. We see ourselves and each other as the solution – that we don't put up with the unacceptable. We can be liked, get invited to the wine and cheese parties and patted on the head, or we can be perhaps not liked but respected.

For me, direct action has been the most powerful tool available to achieve change in both directions, internally and externally. We can only negotiate on a more equal basis and move the status quo if we equalize things with organized action; getting people together. The members of the group get emboldened with moral support. Using the old adage, "two heads are better than one," helps us think and operate outside the box.

Thinking outside the box and coming at a problem from a

different angle is my favorite part! For example, even before the Americans with Disabilities Act existed we wanted to make a local, downtown restaurant accessible. We had asked and they had ignored us. So during the lunchtime rush we set up a card table in front of the restaurant and covered it with a red and white checkered tablecloth, laid it out with paper plates and a meal of baloney sandwiches and put up a big sign that said "Handicapped Seating Section." There were fifteen of us, and surprised customers took our literature. Many spoke in support of us to the restaurant staff – who were either sympathetic or were trying to get rid of us. The mood was tense at times; at others, we grew lighthearted speaking out for ourselves.

Pretty soon the owner showed up with smoke coming out of his ears! We explained we wanted to go inside and spend our money and eat his food. He said "no can do," but a quiet little guy in our group piped up saying, "if you can put a taxi cab on the roof, you can put in a ramp." The owner blinked a few times digesting this, and agreed to meet with us.

We had brainstormed how to handle the meeting, and decided to set a wheelchair in the middle of the room with us in a circle around it, leaving it the only place the restaurant owner could sit. It balanced the power relationship, and his

Outside the Box (cont.)

mood changed as he realized the sense of our request. He agreed to put in the ramp. Later he made the restrooms accessible, brailled the menu, and sponsored a local radio reading program for people with visual impairments.

We've wrapped ourselves in red crepe paper at public hearings to illustrate the red tape that can tie us in knots. We've slept in Governors' offices waiting for a promise to create community living alternatives. We've sucked up our share of carbon monoxide blocking inaccessible buses. These and other techniques can be used for any issue – even freeing our people from nursing homes and other human warehouses. But the best part is doing these things with others and getting results, learning by doing what actually can make a difference.

Life is short. We have limited time and energy. Why not have a good time and spread the work around? Why not be creative? Why not aim high to clean up some of the things wrong with our society?

Self-Advocates Gather in DC

Judy Cunio
Self Advocacy Coordinator
Oregon Council on
Developmental Disabilities

2,400 self-advocates, family members and professionals came together in Washington, DC on September 22-23, 2005, for a history-making event called "Summit 2005: Many Voices, One Vision." More than 70 people from Oregon attended. The purpose of the event was to bring together people from all over the country to work on a 10-year national advocacy plan for people with disabilities.

The event was put on by the Alliance for Full Participation, which is made up of 11 national organizations, including SABE, that work in the developmental disability community.

The Summit showed just how much we do have in common with each other and how we are able to work together and to share ideas.

One of the highlights of the Summit was the Town Hall Meeting. A man who works for CNN led the meeting. His name is Frank Sesno. He also has a sister with a developmental disability.

Advocates Corner (cont.)

The voting process was really good because everyone had his or her own remote control. The Town Hall included most of the people who were at the Summit. There were a number of questions that we were asked to vote on, and I would like to share some of the results with you.

97% of the people thought that with the right supports all people with developmental disabilities could live on their own.

They asked if we believed all people with developmental disabilities wanted to direct their own supports. 77% of the people said yes, 9% said no and 14% said “maybe in time.”

Did we think that sheltered workshops needed to be closed and community options created? 70% said yes and 30% said not yet.

Do labels help or hurt people with developmental disabilities? 32% said that labels help because they drive funding, and 68% said that labels hurt.

Regarding people with developmental disabilities, 77% said American communities are “well meaning but clueless.”

Do concerns about personal safety create barriers to gaining inclusion? 79% said yes.

What is the number 1 issue in the lives of people with developmental disabilities? The top two answers: 32% said lack of opportunities, 27% said dignity and respect.

The most important role of a community provider is to: 61% of the people said “provide service based on individual need.”

People can’t get jobs because: The number 1 answer was the attitude of employers at 45%.

As you can see, no matter where you live around the country, people are saying many of the same things.

**AND SO IT REALLY IS MANY
VOICES AND ONE VISION!**

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

College Life

Linnea Goranson
Portland

I've worked at Portland State University for almost 4 years now and I really enjoy working with the faculty and staff here. Since I started working here, I've been getting a whole new perspective about how to be professional in my position as Office Assistant and Special Assistant. I have had a lot of experiences working with the staff and faculty here. Experiences like getting to know different people and their personalities and learning that they can differ a lot.

I started working here in 2001 for the Graduate School of Education (GSE) and Continuing Education in 2002. My jobs are the same but different. At GSE I copy and photocopy course papers and handouts, mailings including putting labels on envelopes, filing, sorting and delivering mail, delivering confidential papers, word processing, data entry, organize and reorganize different offices, putting papers in student mailboxes.

In Continuing Education (CEED) I copy and photocopy course papers for classes and workshops, word

processing, data entry, mailings, filing, delivering and sorting mail and delivering confidential papers. I've made a lot of relationships while I have worked here and the staff and faculty became my huge family because they act as parents and brothers and sisters to me. I will never forget them. That's why I like to go to work everyday. They help me understand and they explain to me what I see in the world around me.

I also talk to different classes in Special Education (SPED) and I am making a difference to students trying to be teachers in different schools. Recently I talked to other students who are going to be teachers in inclusion classrooms.

I talked to them about my experiences going through General Education plus Special Education. Being a person with a disability and working here at PSU together is a greater challenge and motivation for me and the faculty and staff.

Melvin Bush is a person with cerebral palsy who brings coffee from Seattle's Best to faculty here at PSU. He and I have something in common. We both have a disability and we are people who contribute to society and bring everyone awareness of the diversity and difference in the world.

Dream Come True

Kara Romanaggi
Portland

This fall our big, Italian family gathered at Camp Sherman for my Uncle Kent's wedding. My Aunt Laura and Uncle Mark could not be at the wedding, because they were at the hospital waiting for their second baby to be born. My cousin Beau was born the day after the wedding.

Two days later, when Uncle Kent and Aunt Alicia were back from their honeymoon, Uncle Mark called everyone to come to a family meeting at my grama's house.

When everyone was quiet, Mark asked if I would be willing to take the responsibility of being Beau's godmother. Suddenly, all at once, a dream I'd had for many years had come true. I was going to be a mother, just like my godmother, Aunt Robin, has been to me.

Email your stories to
The People First Connection
mtbclarion@comcast.net

How to Say No

Gayle Bernice Gardner
Portland

It can be hard to say no. You may not want to tell your friends no. You may feel guilty because you say no.

No isn't a bad word. You can't say yes all the time.

You have to protect yourself and learn to be your own person. Set boundaries of what you will and will not put up with.

There are different levels of saying no. I always hope that people will take my word for it the first time I say it so that I don't have to get mad.

If you give in too many times people will come to expect it. People will see you as a doormat.

I have to protect my physical and mental health. I just don't like being manipulated. I must be honest with people and tell them my feelings, not saying OK when it's really not OK. If you do that then people will not respect you and will treat you like a child. That makes me angry, ready to scream.

How do you tell a friend of a friend that they can't come? When you get rid of the messy people, then you have time

How to Say No cont.)

for the really good people.

Realize when you have to say no. Saying no can be a really healthy thing.

Life will give you plenty of opportunities to decide whether you want to say no. Sometimes you will need help and advice to say no.

I can feel uncomfortable and awkward going to a friend. I don't want to go through that again. I have to get assertive.

Sometimes people won't stop until you say no. No is not an easy thing to do. But using the word no to keep your life free of hassles means that you have more time to have fun.

People just have to learn to live with it. True friends will understand.

Sometimes you have to say no when people want you to be on a Board of Directors. Some people might not believe you when you say no.

During childhood you're trained to

say yes, when you really want to say no.

Learning how to say no can be a hard thing to do. People may not like you if you say no.

SAAL News & Plans

Self-Advocates As Leaders will be hosting a Writer's Workshop in La Grande this spring. Participants will receive supports to help them prepare an article for publication in *The People First Connection*.

Violence Awareness Training will be held in Coos Bay on January 21 at the Newmark Center.

To register for these events, learn more information or to schedule a Writer's Workshop in your part of the state, simply call or email Marcie Alvarez.

She can be reached at (503) 725-8129 or toll-free 1-866-835-0659.

Her email address is alvarezm@pdx.edu

Self-Advocates As Leaders needs and wants your participation.

We hope you will join us soon!

Amelia - My Hero

Eleanor Bailey
Portland

Amelia is my friend. She lives in Eugene with her family. I have known Amelia for many years. When I was in fourth grade, I wrote an article about having Down syndrome. Amelia and her family read the article and Amelia sent me a letter. Amelia told me she had Down syndrome too, and she liked my article. Then, our families arranged for Amelia and me to meet. We have been friends ever since.

Amelia is taller than me and skinny as a stick. She wears big brown glasses that make her eyes look wide. Her silky brown hair hangs down straight to her shoulders. Sometimes she wears her hair up and sometimes she wears it down. For a long time, Amelia looked like a teenager with her mouth full of braces. Now, Amelia doesn't have braces. Amelia plays soccer, runs and swims. She likes to listen to CDs and dance wildly like a storm. We like to be weird together and talk on the phone for hours. We giggle with hyperactive laughs.

Amelia talks with other people about how it feels to have a disability. She talks about her life and her school. She talks about being treated differently and how when people look at her in a weird way she feels uncomfortable. Amelia wants to be included in activities and she tells people how it feels to be left out. She wants to have friends and do things with them. She wants people to understand how to be a friend to someone with a disability.

Other people need to learn about having Down syndrome and how it feels. Amelia has given speeches about herself. She wrote an article for the newspaper about how she feels. She has been on television to talk about her disability and how people with disabilities should be treated. I admire her for explaining about disabilities and how she feels.

Memory

Kaitlin Mullins
Hillsboro

There were four, now there are two. I have a poster of them. My mom told me about the rise and fall of The Beatles. One died of a heart attack, and another died by a crazy man.

I'll never forget that there were four, and that they were called The Beatles.

City Bus Blues

Susan A. Melero
Corvallis

People with disabilities in America have rights and we need them. There are some transportation rules in the State of Oregon that need to be changed. You need to call people in your state and community and ask them to change the rules that we need to live.

Our Corvallis city bus runs from 6:45 a.m. to 7 p.m. and on Saturdays from 8 a.m. until 4:45 p.m. On Sunday they don't run at all.

There is also a shuttle bus that runs through the campus at Oregon State University. It runs from 7 a.m. until 6:30 p.m.

When our football team plays home games at Reser Stadium, I usually have to walk. It is worse for basketball because the games don't end until after the buses stop running. We need transportation for more activities.

Dial-A-Ride is also an option that

we do have in our community. That can be good for times when we have to be certain places like a doctor appointment, the dentist and other places too.

But Dial-A-Ride makes us schedule rides a day ahead of time.

We need buses so that we can work things out on our own time. They need to get us where we need to go, when we need to go.

Water and Rain

Kaitlin Mullins
Hillsboro

Waterfalls speak to me. Whenever I'm by a waterfall or even just an outdoor fountain, I think of the beach and swimming in the ocean. I try to imagine the water flowing over me, taking away my stress.

When the rain comes down and makes puddles, I think of the puddles made by my tears. When I hear the sound of rain, I think of the sound of my crying. When the rain falls down on my head, I want it to wash away my tears and drown all my fears.

Rain and water soothe me.

My Vacation

Lisa Olvera
Astoria

In the second week of July, I took a trip with my family to Walla Walla, Washington to visit my sister. When we arrived, I hugged and greeted my sister.

Later that day, she took me shopping at the store. There, I bought a puzzle and a favorite book to read. My sister and I socialized while shopping.

It was around evening time and my sister asked if I wanted to go out to eat. I said “yes,” and we went up to a Mexican Restaurant to have dinner. After having dinner, we drove home. It was getting late so I went to bed.

The next day I got up and got ready to go to church with my sister and her family. I was very excited to see my sister. When it was time to go home I didn’t want to leave my sister.

But she told me that I had to get ready for work on Monday morning. So we left.

Not My Problem

Nancy Jameson
Portland

“Hey, Mrs. Giraffe! Can we hitch a ride?”

“Hitch a ride? What do you squirrels think I am, a bus or something? No way. Get lost. Can’t you see that I’m trying to enjoy the leaves on this branch?”

“Please, won’t you help us? If we can’t climb up on your back, we’ll drown.”

“Not my problem.”

“Please, Mrs. Giraffe, can you spare a piece of that branch for my baby? The flood has covered most of the bushes and my baby hasn’t eaten in four days.”

“Oh, go away. You horses are such a nuisance.”

“Please, just a few leaves. My baby will starve.”

“Not my problem.”

Pesky animals. Oh no, what’s this? Too much water. What to do? What to do? It’s almost up to my head.

Not My Problem (cont.)

“Hey, Mr. Noah. Wait! Don’t close that door. Stop! Please, come back. Come back ...”

“Oh, look at that poor giraffe, Daddy.”

“Come on, son.”

“But Daddy!”

“Not my problem, son.”

We Said It All

**Joan Reid
Portland**

I don’t know how far away it was, only that it was somewhere to the left of me.

I didn’t know whether the voice belonged to a man or a woman.

The one word, “Wow!” came in the moment of silence before the clapping began.

Michael Allen Harrison had written the piece for

a movie, a movie they hadn’t started filming yet; it was that new.

And when I heard the whispered “Wow!” I answered, “Yeah!”

I don’t know if the other person heard me, but in those few seconds, together, we said it all.

Birthday Music

**Cynthia O’Neal
Corbett**

Because my birthday was closest to the date Michael Allen Harrison chose, he gave me his sing-along CD of Christmas Carols. I listened to it for the first time this week. Don’t ask me which song was my favorite; I like them all.

I always feel happy with I hear Michael play, but it’s even better when I can see him, too. He and his best-friend-since-he-was-seven-years-old, Julianne Johnson, came to help us put on a benefit concert for hurricane Katrina survivors. We saw slides of the people who were sad because of all that they had lost. We came together for a serious matter, and we raised a lot of money but we also had a wonderful time.

