

THE SAAL CONNECTION



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

Fall/Winter 2010 #61



WE CAN'T GO BACK!!

By: Judy Cunio, Editor

In the last issue of The SAAL Connection, I wrote about the celebration of the past 10 years of accomplishments that have been made in the DD system. And, we should be very proud of these accomplishments! We have come a long way, but it doesn't mean that it is time to stop fighting for what we want and need.

In this issue of The SAAL Connection, we will help with that fight by sharing personal stories from individuals about what their lives are like with services and what their lives would be like if they were to lose their services.



To gather articles for this issue, I sent out a request for personal stories from people who receive services. Some of the stories I received were written by families. The SAAL Connection Editorial Board decided to include those stories because they help show how important it is to keep our services.

Thanks to everyone who submitted stories. The more stories we can put together from different points of view, the bigger the impact we will have in the fight for keeping our much needed services.

We have come too far to give up now!!

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Stop the Legislators from Taking Away our Freedom

By: Stacey Boyko, Milwaukie, Oregon

I am Stacey Boyko and I'm 21 years old. I have an autism spectrum disorder and I was diagnosed about three and a half years ago.

The budget cuts will affect me because I probably won't be able to keep my in-home healthcare worker after February 2011. I can't lift things, so my worker helps me lift things, helping with the dishwasher and cleaning my house. She teaches me about nutrition, healthy food choices, how to live healthier and to grocery shop. She really helps me to lead a healthier life.

I probably won't be able to keep my Alternative to Employment (ATE) program. I currently work at Full Life and we spend a lot of time socializing. I wouldn't get time to socialize and work if it wasn't for Full Life. It's hard to find a job, and I can't really work in the same way other people do. Full Life is important for people with disabilities like mine because sometimes we get to write poetry, we get to have artistic expression, and it's really powerful. It touches a lot of people's lives. It gives people with disabilities the opportunity to show others that we are able to do things and very capable, and we are just like everyone else.



I think the budget cuts will have a drastic affect on people with disabilities. Back in the 60s, or 40s, people were institutionalized. I'm afraid we'll go back to having people institutionalized and not living in their own homes. Politicians have a hard job because they have to make budget cuts sometimes and I think they don't always know how bad the cuts impact people, especially people with disabilities who are trying to live independently or with families. They want to stay in their own home, not be institutionalized. I don't want to be institutionalized. I deserve a life in the community.

I Am Grateful for these Services

By: Joanna, Eugene, Oregon

I am 40 years old and developmentally disabled. I live with my brother. He works very long hours. I don't know what I would do without the help I am getting from Full Access. They help me do my personal chores and enable me to attend Pearl Buck Center.

I have lost 80 pounds and they help me try to keep it off with exercise. It is also nice to have some company, since I am alone most of the time.

I am so grateful for these services.



Advocacy in Action, My Story

By: Andy Owens, Portland, Oregon

At 22 months of age, I had a drowning accident that left me comatose for seven months and hospitalized for a total of two and a half years. It has now been twenty eight years since my accident and I work at Powells.com as a valued employee. My job was not specially formulated for me, but was a necessary part of the company that other employees were also trained to complete and this last summer was my nine year anniversary. After my accident, doctors predicted that I would be what they called a "vegetable" if I even survived (which they found unlikely). I left the hospital unable to speak in an intelligible fashion and confined to a wheelchair. My diagnosis was cerebral palsy and I had lost my fine motor skills. Adaptations were made by my family and friends to communicate with me, forming systems for feeding and meeting my other needs.



At Powells.com, my parents helped adapt the job to my abilities. I have a personal assistant that helps load books onto a conveyor belt that I can control with switches in my head rest. I also have a personal computer that communicates with the Powell's computer and is also controlled by my head switches. I don't have good control of my arms, so this allows me to do computer work and maneuver books without use of my hands. I use what my family and I have learned from developing my job in order to teach others with disabilities (especially high

school students) that they are also capable of achieving more when they graduate. I enjoy taking college classes when I have extra time and love my job. I am a member of the Washington County Self Advocates, which is a group that helps organize people with disabilities so that they can speak up for themselves and achieve their dreams.



I am only able to work and participate in all of these things through the use of in home comprehensive care. My assistant and caregivers must be paid in order for them to help me work and help others with disabilities become functional members of society. Cutting these services in the budget will force me to quit my job and become a responsibility of the state. I will no longer be paying taxes and I will be costing the state even more money than what my current caregivers require.

My name is Andrew Owens and I have proved many people wrong. I am not a vegetable. I am a hard working member of the community and a voter. I pay taxes and contribute to society, rather than sitting at home watching television all day. I am capable, like many others with disabilities, to help our community function, both through my paid job and my volunteer work.

My Life is Happier with Brokerage Supports

By: Dareth

With Full Access and all that I can do with them, I am Good 2 Go. Without Full Access, I would have no money or access to activities. I would be so depressed. I'd be hard to live with. I would be lonely, depressed and angry. I would be so lost without Full Access and G2G.

My Life would go down the proverbial tubes and that is not a good mix with being born with Autism. I'd be reclusive, lethargic, depressed, not care about me or anybody else, I'd just want to sleep, be alone and get even more depressed. Then eventually, I am so depressed that I am bored of life and living is a terrible place to be. I never want to see that again.

With Full Access I have the ability and desire to build all kinds of friendships and relationships with other people. Also, other people want to build relationships and friendships with me and get to know me better.



I have all kinds of activities to do. I get up and start my day, can't wait to do things, live life, see friends, have fun. I am just an all around better, happier person.

A Friend for Ben

By: Ben

My son Ben, who just celebrated his 28th birthday, continues to thrive as a direct result of the financial assistance we receive through the Staley Agreement. We have been able to cultivate a modest but valuable life together. The Staley Agreement understands that disabilities are often extremely individual in nature, so the funds are specifically allocated to suit the needs of each person.

What Ben most needed was a young person to hang out with. We were fortunate to find that person over 5 years ago. Sean and Ben have a beautiful relationship that centers around movement and outdoor adventures.



As much as we love Sean and he us, he could not provide this service without compensation. I could not imagine life without him. Thank you for your interest and concern in our lives.

**Send your story to:
The SAAL Connection
540 24th Place NE
Salem, OR 97301**

Please Don't Take Away the People Who Care for Me

By: Kristel, Bend, Oregon

I am 28 years old. I am a person with DD. I live in my own studio apartment and work at the Opportunity Foundation where I earn about \$140 a month. I get some disability Social Security money and \$16 in food stamps.

If I lose my services it will be very hard. I will lose my job. I don't drive so I wouldn't have money for the Dial-a-ride. I don't know how to use the bus system in Bend. It is too confusing and I get confused very easily.

I have help with my shopping for healthy food, cooking meals and help to keep my apartment safe and clean. If they can't help me then my elderly parents who live 30 miles away, might have to come to town more or I might have to go and live with them. Then I won't be able to see my friends, since they live a long ways away. I would be very lonely and depressed. I do things at Parks and Recreation, but I wouldn't be able to do that without help. I don't have lots of money. Please don't take away the people who care for me.



Supports Make My Life Better

By: Mindy, Eugene, Oregon

I moved to Eugene eight years ago from Roseburg. At that time I did not qualify to receive any support for employment, but did have an opportunity to attend Lane Community College. While in college I learned to use the computer and many other skills that helped me to find a job.

After my parents were seventy years old, I was taken into a Brokerage and with financial support from the Brokerage and with the help of Alternative Work Source, started working for Peace Health, Patient Financial Services. I continue to get support from Alternative Work Source with my job and with any problems that arise. I really enjoy my job and the people I work with. Also, with the support of the Brokerage, I can have a person take me to shows and other activities that I enjoy.

Without the support I am getting now, there would be no job for me and I would have to stay home, most of the time watching television and not be able to go out in the community and do all the activities that I enjoy.

Life Stories Workshop

Call Marcie for more
information at:

503-725-8129 Portland area

1-866-835-0659 Outside of Portland area

Freedom for Me and My Family

By: Monica, Cottage Grove, Oregon

Because of the services I receive from Full Access through the brokerage system, I have a wonderful life. They have helped my parents to have the opportunity to travel without me by providing respite. They also help me to become more independent of my parents by providing an opportunity to get out in the community with a support person.

I also recently got a new job as an office worker, which had been a dream of mine and was trained and supported in my job by a supported work provider. Please don't cut these services, as they are helping me to become more independent and included in my community.

My Job Means Not Just Sitting at Home

By: Trent Minor, Stayton, Oregon

I'm a volunteer for the activity department at Marian Estates, an assisted living complex. I enjoy participating in the activities with the residents. When there are not activities, I visit with different residents. I sit with the residents to make them more comfortable. Sometimes I eat lunch with special residents. For activities we play bingo, listen to music, do crafts, and have church services.

I need some special support staff in order to do this work. I am hoping that budget cuts do not affect this. This job means so much to me and to the residents that I spend time with. I

would just sit at home if I did not have this job. I like to be busy, not just sitting.

Everyone Deserves a Happy and Fulfilled Life

By: Stephen, Madras, Oregon

I am a 20 year-old with Autism. My sister is helping me write this letter. Everyone that has met me says I'm a really friendly person. I'm always happy to help and share with people. I like talking to them about music and animals, my two favorite things. I feel that there is no reason to limit myself in who I want to be and what I can do.

I love the drums. I am hoping I can take a class or have a personal instructor, so I can become a better drummer. I have been drumming in my church for about 8 years now. It is something that I feel really special about.

I enjoy working at the Opportunity Foundation Thrift Store. Sometimes I help people reach things that are up too high because I am tall! I like learning how to be organized and following a routine. I am so thankful for being able to work and for the help that is given to me. It makes me feel like I am a valuable member of my community and that people care about me.



This story continues on next page.

There are so many other people like me who just want to grow and contribute to our world. We are very fortunate to have the resources that have allowed us to do so and my hope is that it will continue on. Everyone deserves to live a happy, fulfilled life and to improve themselves. Thank you for your time



My Freedom Means Everything By: Tony

My name is Tony and I receive services from Full Access in Eugene. The biggest way they've helped me is by helping me to find an apartment. They also helped me get a job and helped me find resources like food stamps.

Without the support I've received from Full Access, I would still be living with my parents and having difficulty getting a job. I wouldn't be living independently as I am now. If these services went away, I hope I'd be able to keep my apartment, but I would have no one to help me fill out important paperwork or to help me find a job.

Please Don't Turn a Blind Eye By: Sarah

I am a person with a developmental disability. My life definitely has many challenges and obstacles. I have a hard time navigating the community.

My day to day routine has extreme challenges. My support system is made up of The Mentor Brokerage in Portland and of course my family. It is very necessary for me to continue to receive my brokerage funding. Without it I would be unable to be as mobile as I am. I would not thrive as a person; I would not be able to be as independent as I am. I fear I would lose the pride and confidence I have begun to have in myself.

I do realize our economy is in crisis, but why are our US Representatives giving themselves a pay raise? Why was my much needed Social Security money not given a cost of living increase? Why do the less fortunate always get left behind?

Please do all you can to keep my funding. I feel sure that all disabled persons feel the same way. It's just that not all of us can speak for ourselves. Please don't turn a blind eye to our continued needs. We don't want to be treated like we don't matter. Let me have pride in the life I have. Thank you.



Please Don't Take Our Services

By: Robert Costa

Hello my name is Robert Costa. I live at home with my parents. I have cerebral palsy, due to a blood clot on the brain at birth. I am a quadriplegic and have had six major surgeries. I'm mentally and physically handicapped. I could not survive without the total care of my parents.

I need 24-7 care. I live in a world of my own and I really don't understand a lot. I can talk clearly but live in a very severe hypertensive state, due to my condition. My parents and people around me have to be careful of what they say because I misinterpret what's being said and get very agitated easily.

I need total care in bathing, transfers, dressing, toileting and all hygiene. I also need assistance with feeding and all my medications twice daily, to maintain my condition. I'm pre diabetic.

My body is very spastic so rather than sit in a wheel chair I sit on the floor on a special mat. That way my body is less rigid. I talk constantly about anything and everything that pops in my brain. My world consists of jingling keys, changing batteries in my radios and music is my world.

My parents and I are on social security. The extra funds they receive help us live a little more comfortable quality of life. If this was taken away it would have a dramatic impact our living conditions. I surely hope and pray that this won't happen because a lot of

people like me will be jeopardized for the quality of life they now have. The funds from the state of Oregon have been a blessing to us.



For Me, ISN is a Gift

By: Renae

I am an ISN (Integrated Services Network) customer and have been receiving services for a while now and have enjoyed what I can do and have learned. In my few short years I have been able to enjoy the thrill of going to camp in the summer, the patience of learning how to volunteer in my community, and enjoying the embrace of friends. I have grown and am learning how to be a good and responsible boss. This has been challenging for me, but how sweet has been the reward!

Books are one of my passions and now I've learned how to volunteer at a public library. I can now volunteer at the library on my own.

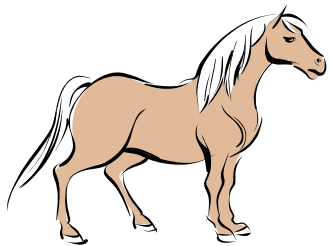
I am now getting the opportunity to be tutored which is a sweet gift for me because I love to learn and I wanted to learn. Because of a provider's willingness to try and teach me, I can have a second chance at learning the basics of education. This is something that I have wanted ever since I finished high school.

This story continues on next page. 8

Another gift ISN has given me is the ability to often be a part of my community. I live in a rural area and do not drive. Thanks to my providers I have the opportunity to be a part of my community that otherwise wouldn't be possible.

ISN has given me peace of mind. I do not do my own bills and I have a responsible and trusted person who helps me with that. That peace of mind is a huge relief and freedom to me monthly. ISN also helps me with taxes and that is a big help and a huge relief to me. It may seem like a little tiny thing but for me it is a life saver.

I have been able to be involved with a horse program that has helped me communicate better. It is teaching me to be more calm and has given me physical relief. To be able to touch a horse and groom it is very therapeutic for me.



ISN gives me friends, opportunities, challenges, but mostly it has given me a way to be free.

I Love My Life

By: Joni, Salem, Oregon

My name is Joni Lynn Wayne. I am 15 years old. I have an older sister, and a younger brother and sister. I was born in a hospital in Salem. My birthday is December 29th, 1994. I go to South

Salem High School. I love cats. I love art. I like to climb trees and rock walls. My favorite color is orange. I'm a fan of the Beavers. I love Twilight. I've seen the first and the second movie. But I really want the third and the fourth one. I love my life and I always will. I like a boy.

Oregon's Services are Better

By: Cathy

I moved to Oregon almost two years ago. It will be two years next month and I started with Lura about two years now. The services are great. They are helping my brother Chuck and me a lot. Lura is both mine and my brother Chuck's social worker. Lura is helping me find a person who will help me with my housework and do activities with me. At this point Lura will be setting up interviews with a couple of people who are interested in working with me. I wouldn't be getting this kind of service where I used to live. They don't have this kind of service for people like me. Well, not as good as the service here in Oregon. The people here at Full Access are very helpful and very kind. I enjoy being part of Full Access and their services are just great.

Thank you for great services!



I Need My Van

By: Nathan

My mom, Susan, is my guardian. We live in our home in the country where I have lived since I was four. I love my mom and I love it here. The house was built with my special needs in mind. My sister, Patricia is my other guardian. She is in Afghanistan with the 82nd Airborne working as a Psychologist with the troops who need help. I am really excited to have her home safely soon. She lives in North Carolina when she isn't in Afghanistan and she "skypes" me so we can "see" and hear each other each other. My brother lives in Idaho and he "skypes" me too. It is important I always have a computer that works so we can stay in touch. My computer was broken for two months. My Mom and I weren't happy campers.

My brother and sister, my niece, Isabel, and best friend, Jeremy always make me smile. Some of my friends make me laugh. I laugh so hard they start laughing, too. At Kiwanis Camp last month I got the Award for Best Laugh.

Two weeks ago, my van was stolen. It is a special van my mom bought so I could get in to town to see friends and do things I like to do. Because we live in the country, the bus only comes by three times a day. Without my van I cannot get to the bus or town.



My mom started a business last year after she retired. She has a restaurant and is starting a new day program for young adults with disabilities, next door to the restaurant and bus station. She pays taxes to the bus company for both businesses, but they cannot send a handicap van to my house except when I have a medical appointment because I live in the country and not the city. Medicaid will only pay for doctor, dentist and eye doctor appointments. It costs \$25.00 to go one way to the Orthodontist or Wheelchair clinic or to do something fun with my friends.

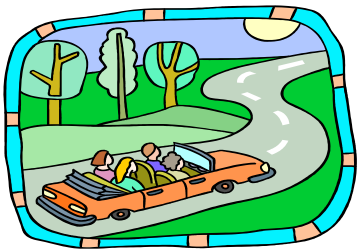
Money I get to use from Oregon and Medicaid helped to pay for the lift that had to be replaced in my van two years ago. It helped to build a sidewalk ramp off the back deck so I can get out of my house in case of fire. It also helped me to get a swing lift that helps me get into my hot tub.

Waivered dollars helped pay for me to go to Camp Kiwanis this year. It was really important for me to go because my Mom and I BOTH needed a break.

My Mom has a bad back from many years of lifting me. She was going to have to have surgery before she got my van. Now she is sad because she doesn't know how she is going to be able to take care of me anymore. The police can't find who stole my van or where they took it. They think it was stolen from us so they can steel things from other people and also sleep in it. This story continues on next page.

I want people in the government to know that when you can't walk, or see, or talk, or hear very well, life isn't always easy. If they couldn't walk, talk, see or hear very well, they would have trouble doing their job. My job is to lift people's spirits. (My mom says I am the "kind of kid that will break your heart, but lift your spirits.") I need your help to be able to keep doing that. If you can't help my mom, then I can't do the job God wants me to do.

Supports, the Road to Independence By: Debbie



I can't imagine our daughter or any other young people with DD, not having access to transportation, care and social support. Our daughter couldn't afford to work or do the weekly community service she does without the support from Full Access. It costs her \$25 round trip for transportation where ever she goes. There goes a 3 or 4 hour shift of wages completely! We know most of the young adults with DD because we keep our daughter active, that is their only safe social life. We are also active in Special Olympics.

The thought of the loss of these services to people in our community that work so hard to find jobs and volunteer their hearts out because they love it, just makes me sick. Our community would suffer as a whole, but not as much as taking away what

little independence and socialization, that people with disabilities have in their lives.

Brokerage Services and My Girls By: Crystal

I am the mother of two daughters both of whom have severe autism. Here is our Story. My daughter Reina has autism, global developmental delays, life threatening food allergies, asthma, and Type1 Diabetes. Reina needs around the clock support with her personal care, medication, blood sugar monitoring, nutritional needs, behavioral, and sleep issues. My daughter Tia has autism, global developmental delays and life threatening food allergies. She also requires around the clock support with personal care, behavioral and nutritional needs. The programs we depend on are Personal Care 20, Family Support funds and The Families Connected meetings through the ARC of Lane County. We depend on these programs for a variety of reasons. These include community inclusion, support and equipment that helps make mine and my children's lives easier. As well as respite care so that my husband and I can catch up on chores or just take a few moments to ourselves.

I can't imagine how scary and lonely it would be for us to try to support our children without these programs. I have very few people in my life who are even capable of helping me with my children and now I can no longer offer them any compensation for doing so.

In Memory of
Rosella Samuelson
January 31, 1947
To
October 8, 2010

BECAUSE SHE REFUSED TO GIVE
UP WHEN TIMES WERE TOUGH OR
TO FOLLOW THE EASIER PATH...

BECAUSE SHE STOOD UP FOR
WHAT SHE BELIEVED IN AND
WASN'T AFRAID OF WHAT PEOPLE
THOUGHT...

BECAUSE SHE LEARNED FROM
HER MISTAKES AND WAS BRAVE
EVEN WHE SHE WAS UNSURE OF
WHAT WOULD HAPPEN NEXT...

BECAUSE OF ALL THIS AND SO
MUCH MORE, ROSELLA WAS AND
WILL CONTINUE TO BE AN
INSPIRATION TO US ALL.

TO HONOR HER MEMORY, LET US
LIVE OUR LIVES AS SHE DID
IN FAITHFULNESS
PERSEVERANCE
COURAGE
AND JOY



My Heartfelt Thanks

On October 7th, 2010 much to my surprise, I received the Support Award "for extraordinary support of both SAAL and the self-advocacy movement in Oregon." What a great honor! What a wonderful sendoff!

As many of you know, I plan to retire at the end of December after working 16 years for the Oregon Council on Developmental Disabilities. What I value most about my time with the Council are the friends I've made while working side-by-side with advocates to make Oregon a better place for people with developmental disabilities and their families. Making friends while making a difference - what more could you want?

Thank you for all the support you have shown me over the years. Thank you for your friendship. And thank you for your dedication as advocates.

Bill Lynch



Self Advocates As Leaders News

Advocate of the Quarter



We are pleased to honor

Jerry Buchanan

Jerry of Springfield, Oregon has done an amazing job, especially for someone who is new to self-advocacy.

Jerry got involved with People First of Eugene in 2002 and quickly began helping out more and more at events. He is now the Vice-President of People First of Eugene, and helps out at all kinds of events, including the annual camp-out along the coast. He helps set up tents, fills air mattresses for people.

Jerry has become a mentor for a woman who has epilepsy. Jerry knows what it is like to be epileptic and he helps others rather than letting it slow him down.

He votes in elections, even the primaries. He is learning ways to be an even better citizen and community advocate, and is learning a lot at school where he takes classes to further his education.

He has shown what it means to be empowered through self-advocacy! Keep up the great advocacy work, Jerry!

Kudos!

SAAL Calendar of Upcoming Events

A NEW SELF ADVOCACY GROUP STARTING IN BEND!!!

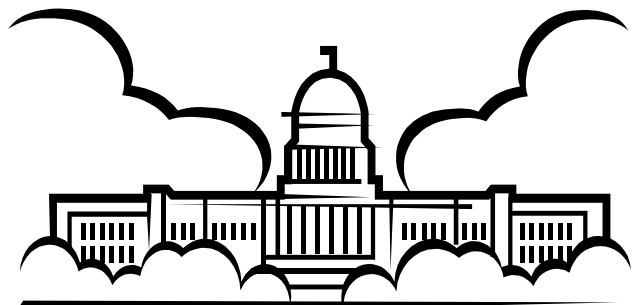
When: March 25, April 15 & May 13

Where: Deschutes Public Library

Time: 4:00pm to 6:00pm

For more information contact: Anna

541-749-2158



SAAL TRAININGS:

SAAL offers training in the following areas, and can also design training based on the needs of individual groups:

- Self-Advocacy 101
- Self-Determination for Everyone
- Supporting Independence (How staff can better support people)
- Violence Awareness: How to Protect Ourselves from Abuse
- My Voice, My Choice
(How to advocate at local, state & federal levels)
- Communication Styles and Effectiveness
- Sexuality 101
- Voting Workshops
- And more

Life Stories Workshop

Bring a
Life Stories Workshop
to your area

Contact Marcie Tedlow
503-725-8129
1-866-835-0659
alvarezm@pdx.edu

To host a training in your area,
call Marcie Tedlow:
503-725-8129 (Portland) or
1-866-835-0659 (Outside of Portland)

Self Advocates As Leaders
3886 Beverly Ave. NE, I-21
Salem, OR 97305

www.asksaal.org



Emerging Leaders Northwest Mentorship Opportunities

Emerging Leaders Northwest is seeking youth member leaders for its advisory committee! ELNW is a youth led resource center for young people with disabilities ages 13 - 30 which provides training and resources on leadership, independence, graduating from high school diploma and going on to college, self-advocacy, employment skills and living a healthy lifestyle. Youth leaders facilitate training for their peers and act as mentors. Leaders may also gain valuable employment experience by participating in internships in business and non-profit entities.

Our meetings are held the fourth Friday of each month from 1:30 - 3:00 PM at the Child Development and Rehabilitation Center, Room 1125, 707 SW Gaines Street, Portland, OR 97207. Please feel free to send an email or give me a call if you have questions about ELNW.

Charles E. Davis, MSW
Community Liaison, UCEDD
(503) 494.3281 (p)
davichar@ohsu.edu
<http://www.ohsu.edu/cdrc/>

MEETING



The SAAL Connection
540 24th Place NE
Salem, OR 97301

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