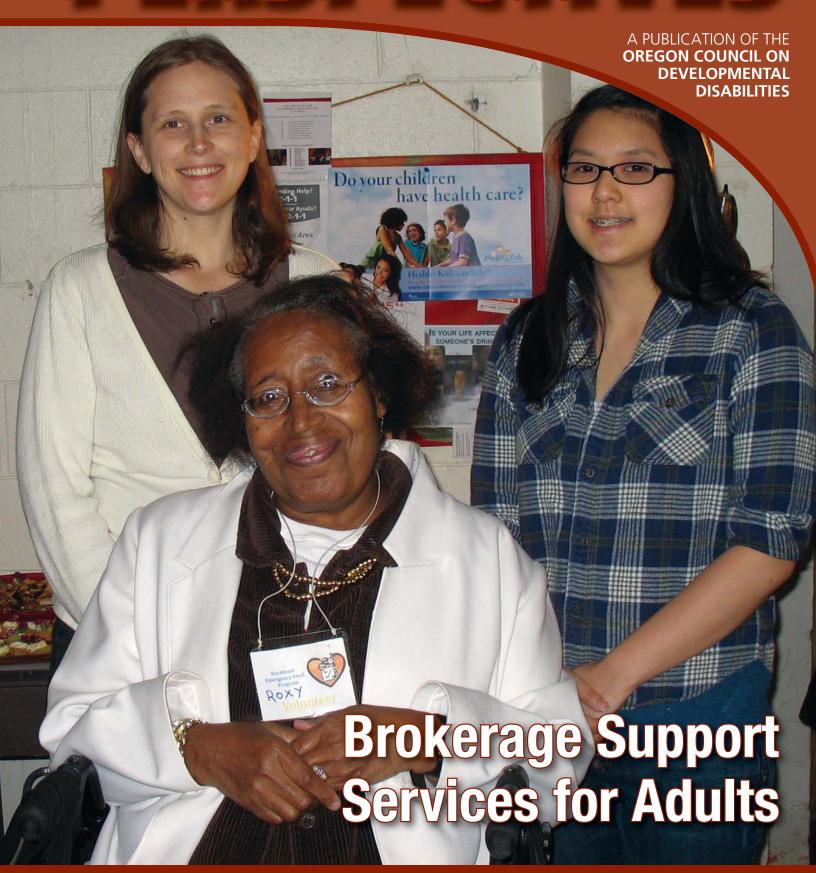
oregon SPECTIVES





The mission of the Oregon Council on Developmental Disabilities is to create change that improves the lives of Oregonians with developmental disabilities.

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COVER: Roxy Dollar with Jennifer and Jaclyn at the North East Emergency Food Program ©2010 Oregon Council on Developmental Disabilities

Note from the editor, Yoshi Kardell:

As this will be my last issue of *Oregon Perspectives*, I would like to share how much I have enjoyed my work on this magazine over the last few years. I want to extend my gratitude to all who have contributed to this publication and shared with us your struggles, successes, and dreams. It is through your stories that we are able to shed light on important issues, teach others about what is possible, and help shape a positive future for people with developmental disabilities and their families.

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From the Director

What a Difference Support Makes

A small amount of support can make a huge difference in the lives of people with developmental disabilities. The difference between isolation and community involvement, loneliness and companionship, depression and a zest for life. As I read the stories in this edition of *Oregon Perspectives*, I was struck by how often people reported that brokerage support services helped them deal with these issues. Not through counseling, but by getting them out of their homes and into their communities doing things they love to do, meeting people, and contributing. A brokerage director recently told me about a person who had made a serious attempt at suicide before enrolling in the brokerage. That same person now reports being happy. While this may not be a typical story, it certainly makes the point that these services can be not only life enhancing but sometimes even life saving.

In the year 2000, advocates struck an agreement with the state to make self-directed support services available to every qualified individual who was not receiving comprehensive, 24-hour services. But two dark clouds hang over the future of support services: the June, 2011 end date of the Staley Settlement Agreement and the abysmal condition of our state budget. Together, they pose a very serious threat to a system of services that has had a huge positive impact on the lives of thousands.

This year the developmental disabilities community celebrated a decade of accomplishments, including the creation of support services now available to nearly 7000 individuals. Yet, how quickly the cheers of celebration have been replaced by the fears of termination. Freezing enrollments would mean that many young people finishing high school would once again take a place on the couch instead of taking an active role in their communities. And cutting these services would be a punch in the gut to people who have finally gotten a taste of what it feels like to be valued, engaged members of their communities.

I urge everyone who reads this issue of *Oregon Perspectives* to get involved in the advocacy community's efforts to save these services. Send us your stories, join the Oregon Disability Network (www.oregonddcoalition.org), and respond to the DD Coalition alerts and calls to action. We owe it to all those who have worked so hard to establish and deliver these services, and most importantly to all brokerage customers current and future who may, through support services, experience a new-found sense of self-worth and happiness!

Bill Lynch Executive Director Oregon Council on Developmental Disabilities





Brokerage Provides Hope for a Better Future

When Donald Scott was getting ready to transition out of high school in 1994, his mother, Nona, called their county's developmental disability program to see what was available for her son after high school. This was before brokerages were developed to provide support services for adults. Nona was told that, since Donald was not in crisis, the only option was to get him on the waitlist for noncrisis, twenty-four hour services. To make matters worse, she was told that only one or two vacancies for these services became available each year. After hearing that bleak news, Nona called her mom and cried for an hour



Donald Scott in front of his home

She was resolved to create a better future for her son than having him sit on a waitlist for years.

Then Nona's determination kicked in. She was resolved to create a better future for her son than having him sit on a waitlist for years.

When Donald was still a young adult, the Scotts arranged for him to move to a private group home. When that home folded, Donald and his parents agreed that moving back in with mom and dad wasn't the best option for him. They all wanted to find a way for Donald to live more independently.

Through networking in the community, they discovered that a family friend of theirs had a son with disabilities, Jeff, who had an apartment and needed a roommate. It seemed like a good match, and it all came together at the right time. Donald and Jeff have lived together for over five years now, and they both receive support from their families and from Self-Determination Resources, Inc., a support

Continued on page 4

services brokerage in Washington County. Nona says, "The brokerage services have really helped make this happen."

Jeff and Donald have the same personal agent, Mary Oliver. She has been with them since the beginning, and they have developed a trusting relationship with her. Mary helps with problem solving and acts as a mediator when issues arise at home.

Donald is really starting to apply what he is learning, and it is increasing his independence and self confidence.

Donald takes full advantage of what is offered through the brokerage. He has worked as a janitor for several years and with his brokerage dollars, he now employs a job coach who checks in about twice a month. The job coach also provides support when things come up at work.

Eating healthy food has always been important to Donald. He uses brokerage dollars to hire a cooking instructor, Cindy Otis, to help him shop and prepare meals. Cindy was hired to provide joint cooking lessons for Donald and Jeff, but they found it works better for each of them to have one-on-one time with her instead, because of their differing skill levels.

During their time together, Donald and Cindy work to create a menu for the week. "She is so great and wonderful. I'm happy to see her. She really helps me," says Donald. Cindy also helps with food safety, such as teaching safe food handling and storing. Donald is cooking meals from scratch two nights a week now, one with Cindy and one on his own. The rest of the week, he usually prepares Healthy Choice frozen meals.

Nona feels that Donald is really starting to apply what he is learning, and it is

REQUENTLY TANKED ASKED OUESTIONS

How did Brokerage and Support Services for Adults get started?

Support Service Brokerages are the result of a class action lawsuit brought against the State of Oregon in 2000. The lawsuit was filed by five Oregonians with developmental disabilities who were eligible for services but had been on a waitlist for years. The state entered into the Staley Lawsuit Settlement Agreement that obligated Oregon to develop support services for everyone on the waitlist. During the past decade, almost all those identified as waiting for services were enrolled in brokerages. increasing his independence and self confidence. For instance, once he had planned to make a halibut meal with his cooking instructor. However, when he went to the store, they were out of halibut. Donald decided that he would make tacos instead and bought all of the ingredients to make this meal. He was very proud of this accomplishment. In the past, he would have come home without purchasing any groceries.

Donald likes living on his own. He has a full social calendar between work, bowling, and getting together with friends to play games. When asked about the brokerage and his personal agent, Donald says, "Mary really helps me a lot on my plans and working on my goals, such as being more independent, getting more time in the community with friends, and going places."

"Because of the brokerage system, we have a feeling of hope now," says Nona. "Parents don't always get told that there is hope for their child. It is important for parents to know that high school is not the end of supports."

What are Support Services?

Support Services are paid services and supports provided by a group of independent support service providers. Support services can include community inclusion supports, skills training, respite care, non-medical transportation, chore services, accessibility adaptations, supported employment services, and other supports.

JOIN THE OREGON -Disability-NETWORK



A project of the Oregon Council on Developmental Disabilities and the Oregon Developmental Disabilities Coalition

- Receive important news alerts via e-mail and take action on issues critical to people with developmental disabilities and their families.
- Join a collaborative network of people who experience disabilities, their families, friends, advocacy partners, providers, and policymakers.
- Learn about useful resources, trainings, forums, and speakers of specific interest to the developmental disability community.
- Visit the Oregon DD Council Website for a link to the network or go directly to http://ornet.eactionmax.com/signup.asp to become a member.





From High School to Adulthood – Brokerage Gives Family a Jump Start

Paul Fleck is a young, outgoing guy who is yearning for more independence. He has a strong interest in music, and he performed in an opera at the Hult Center for the Performing Arts in Eugene. Paul graduated from Churchill High School in spring, 2010 and is determined to one day live in his own apartment. But for now, he has decided to take advantage of the school's Community Living Program (CLP) for students with disabilities from the time they graduate through age 21. The program is giving Paul an opportunity to sample a variety of jobs to help him gain skills and explore the type of work he might like to pursue.

Paul was put on the list to receive brokerage services as soon as he turned eighteen. This was ideal so that he could begin planning for transition during his last year of high school. Paul started receiving brokerage services last summer from Full Access in Eugene. Paul's mother, Nia Fleck says, "Connecting with the brokerage has given us a jump start."

Through his personal agent at the brokerage, Paul was referred to Supported Employment Service (SES), which helps clients secure and maintain employment. SES also helps some clients, like Paul, manage their money with assistance from a representative payee. This "rep" payee is primarily responsible for making sure all of Paul's bills are paid. Full Access funds the support he needs to learn how to budget and put some money in savings, which is a great source of comfort for Paul and his mother. Of course, being the independent-minded

REQUENTLY ASKED ASKED QUESTIONS

What is a Brokerage?

A brokerage is a private organization created to help adults with developmental disabilities identify their support needs and assist them in meeting their goals in a costefficient way with help from Personal Agents. Currently 12 brokerages operate throughout the state.

What are Personal Agents?

Brokerage Personal Agents (PA) act as liaisons between the provider and the customer. The PA supports the self-determination of brokerage customers by helping them identify their goals and support needs and by helping them create a plan to meet these goals and needs through paid and natural supports.

guy that he is, Paul's goal is to manage his money on his own one day.

Dawn Aubrey is Paul's personal agent at Full Access brokerage and coordinates the services he receives. She also helps him find solutions to problems when they arise. SES contacted Dawn because they noticed a difference between the amount of debt that Paul reported and what his mother had reported to them. Because Paul is eager to become an adult and take responsibility for his spending, he was including in his financial debt the money he felt he owed his mother for certain expenses. During a team meeting, they discovered that Nia did not expect Paul to pay her back for those expenses and instead hoped that he would be able to save for his own apartment. The team worked together to clear up the matter and also develop a detailed budget agreeable to both Paul and his mother.

When new customers enroll in a brokerage, personal agents meet with them to learn about all aspects of their lives, help determine what supports they need, and then assist them to put those supports in place. During one of their

initial meetings, Dawn asked Paul about transportation and whether he wanted to learn how to take the bus so he could get around independently. Paul replied, "Oh no, I don't need that. My mom takes me everywhere I need to go." His mother quickly responded, "I'm not going to do that forever!"

Paul understands that living on his own will come with added responsibilities.

Eventually they all agreed that it would be a good idea for Paul to learn how to take public transportation and get comfortable taking the bus. Dawn referred Paul to Alternative Work Concepts and Lane Transit District, and he was able to take part in a training program they provided on how to safely access public transportation.

Paul also uses his brokerage dollars to hire a provider who is helping him reach

Continued on page 8

What is Self Determination?

Self determination is the philosophy that drives support services. Self-determination is not a type of service, but a way of thinking. It is based on the principle that individuals should have the freedom and authority to direct their publicly-funded supports in a responsible manner based on their individual needs.



his goal of living independently. Paul and Nia interviewed two people from the list of eligible providers maintained by the brokerage. The provider they chose, Ted Barker, has been helping Paul look for an

Ted also works with Paul a few hours a week on cooking skills, including safe meal preparation and food storage.

apartment by finding affordable housing options, filling out housing applications, and arranging tours of the facilities. Many of the available affordable housing units in the area currently have waitlists, and Paul is waiting for an opening. "I am very picky about where I want to live," says Paul. Ted also works with Paul a few hours a week on cooking skills, including safe meal preparation and food storage.

Dawn says, "I'm surprised at how quickly he is learning to be so independent."
Nia adds, "Paul has really stepped up to the plate and is now doing many of the things that I used to do for him, such as picking up his prescriptions and managing his medications. Paul understands that living on his own will come with added responsibilities."

At least once a year, Paul, Dawn, and Nia meet to review his Individual Support Plan (ISP). As changes arise for him throughout the year, Dawn updates his plan so his current needs are always being addressed.

Paul's story is a great example of how brokerage services can help support a smooth transition from school to the community for young people with developmental disabilities, especially if they are in place early in the process. Paul says, "I wasn't sure what was going to happen after high school. I feel pleased and comfortable that Full Access is helping me figure these things out."

Full Access Wins Best of Non-Profits Award

On September 29, Oregon Business Magazine awarded Eugene-based Full Access brokerage with first place in a statewide competition for the top 100 non-profits of Oregon. Full Access won the top prize for a medium-sized agency.

An employee survey was conducted by the magazine to analyze agency features such as benefits and compensation, work environment, flexible schedules, diversity fair practices, treatment of employees by supervisors, career development and use of sustainable practices.

The survey noted particular strengths of Full Access such as: clarity of mission and purpose, pride and belief in the organization, trust in top management decision-making, and the ability of employees to balance family and job obligations.



Brokerage Makes Home Life Possible

he Helms family faces extraordinary daily challenges caring for their 19 year old son, Chris Reid, who has developmental disabilities, and yet they are unwavering in their commitment to keep him at home. Chris has autism and chronic epilepsy due to a genetic condition. He requires constant supervision, behavior support, and assistance with his personal care, such as dressing, eating, hygiene, and toileting. Chris' ability to communicate and complete even simple tasks is quite limited.

The family has built Chris a unique support system with funding through brokerage support services to meet his individual needs. Some of the budget he receives through Integrated Services Network (ISN) is used to hire his mother, Theresa Helms, and this allows her to stay at home with him as his primary care provider. "We invest a lot of time in caring for Chris. It has taken over our lives. This is all I know anymore," says Theresa.

Providing care for Chris is complex and requires an endless amount of energy. He is an early riser and usually gets up between two and four in the morning, and from that point on he requires someone to be with him at all times. Sometimes he has seizures throughout



Chris Reid with his communication device

the night, and on those nights Theresa doesn't get any rest. "I'm not sure how other people use their respite care, but I sleep!" she says. For medical appointments, Chris requires two people

"We invest a lot of time in caring for Chris. It has taken over our lives. This is all I know anymore."

to assist him. He doesn't like to have more than one person in the car with him at a time, though, and becomes agitated

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and combative, so the second person has to drive separately and meet them at the appointment. The brokerage provides mileage reimbursement for the second driver.

Chris benefits from having a daily routine and structure. Every day, like clockwork, he watches his favorite television program. Some of his favorite activities include going on walks and playing games. On certain days they go out into the community and always shop at the same stores so he knows what to expect. Chris has limited verbal communication and uses gestures and pointing to express what he wants. He enjoys it when other people come over to the house, although too many people can become overwhelming for him. According to Theresa, "He can be kind of wild sometimes." They used some of his brokerage dollars to pay for a behavior specialist to assist in developing a behavior support plan for Chris, which has helped tremendously.

Theresa provides the majority of his care and receives a much needed break through respite care providers. Theresa's ex-husband (Chris' stepfather) Randy, is hired with brokerage dollars as a respite care provider. His other care provider, Serena, is the same age as Chris and has known him for many years. They grew up together and have a great relationship.

Chris and his family are constantly contending with his epilepsy. He used to have such violent seizures that they would have to take him to the emergency room. In 2004, Chris had brain surgery

to alleviate his seizures, although they have not gone away completely. The nature of his seizures has changed, and it is critical that Chris' care providers know him really well. They must be able to pick up on the subtle changes in his behavior which indicate he is having a seizure. For example, when his eyes fixate to the right and his skin turns red and blotchy, he may be seizuring.

"The benefits of Chris being able to stay at home with his family are huge."

There is more to this story. Chris and his two older brothers all were born with the same disorder. Sadly, the oldest brother passed away due to severe seizures. Chris' other brother, Pat, displayed very violent behavior and required a higher level of care than the family felt they could provide at the time. In order for Pat to get the services he needed, Teresa had to give custody of him to the state and place him in foster care. "We didn't know what the laws were. Now we don't have any rights, and there's nothing we can do as parents to advocate for him. He has not flourished in that environment."

Life has been much different for Chris. He is part of his community, and everyone knows him. Other family members call every night to talk to him. When brokerage services were first introduced as an option, Theresa was skeptical because of her previous experience

with her son Pat in foster care. She was pleasantly surprised when she met Joan, Chris' personal agent, and learned about how they could arrange the supports based on what Chris needed and keep him at home.

Theresa is thankful for the supports Chris gets, but she doesn't rely on the brokerage to cover everything he needs. Recently, his family had a fundraiser and raised enough money to purchase a communication device for him. "The benefits of Chris being able to stay at home with his family are huge," says Theresa, "not only for his physical health but also his mental health and growth. Chris is in a stable and loving environment with his own family, and as a result he continues to thrive and make progress every year. Chris is a loving and kind young man, and I do believe that is because he has always been with the people who love him. Without the help and support of ISN, I feel my son's future would be a sad one."



Brokerage Eases Parents' Fears about Son's Future

Gwen and Jack Fitzer are both in their mid-eighties. They used to worry about the day they would no longer be around to care for their son Robert, who has developmental disabilities. They did not want him to go to a group home and knew they had to be proactive in order to make sure that didn't happen. They decided that all three of them would move to Oregon from Texas to live with their older son, who had relocated to Eugene and had offered to share his home with his brother. They wanted to get Robert comfortable and established with his brother, and then, if necessary, Gwen and Jack could transition to an assisted living facility.



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Robert Fitzer and his dog, Lady

Since services for people with developmental disabilities differ from state to state, they had to learn about what services were available for Robert in Oregon. They started by getting him enrolled with the County Developmental Disabilities Program. Knowing the move was going to be a difficult adjustment for Robert, they wanted to get him involved in activities outside the home right away and help him get familiar with a new routine. This was not only important for his transition, it was also critical in order for Robert to live with his brother long-term.

They used to worry about the day they would no longer be around to care for their son...who has developmental disabilities.

Gwen and Jack began paying outof-pocket for Robert to attend a day program at Pearl Buck Center. They were impressed with the services offered at the center, and Robert really enjoyed the activities there. They knew that Robert would always require a lot of time and effort on the part of his older brother, but they did not want him to also become a financial burden in the future. They began to look for some funding sources and were referred to

"I encourage other parents to start early in planning for the future."

Mentor Oregon brokerage. Fortunately, Robert was eligible for brokerage support services, and they enrolled him. "Rob's personal agent, Ed Little, has been tremendous," says Gwen. "He bonded with Rob right away and always included him in every decision. At first the option for Rob to use his brokerage dollars to keep going to Pearl Buck was denied, but Ed kept persisting until it was approved."

Robert's family helps him get out into the community. One of his favorite things to do is go to plays at the local children's theater. His brother and nephew often take him out to eat or go shopping. He also uses his brokerage dollars to pay for public transportation, which increases his independence. He has learned to take RideSource, a public transportation service for people with disabilities, to get to and from the Pearl Buck Center.

The Fitzers now have peace of mind knowing that they have done everything they can to prepare for the future and that Rob will continue to live in a familiar environment with his brother. This is possible largely due to the supports that have been coordinated through Mentor Oregon brokerage.

"I encourage other parents to start early in planning for the future," Gwen says. "It's important to have things in place."



Brokerage Provides Essential Support for Transition from School

Sarah DeWeese is a very busy and cheerful girl. She recently finished her senior year of high school, and she is a volunteer at the local retirement center, a Special Olympic athlete, and an active youth group member. Sarah has a very positive disposition and is always smiling and giggling. Until recently, her parents and several others close to Sarah were concerned about what would happen when she leaves the social structure and active schedule of high school.

Although Sarah has met the academic requirements to graduate, she will be receiving school-based transition services. Leading up to this year, her parents, and her Individual Education Program (IEP) team had been working to develop her post high school transition plan. The school wanted Sarah to possibly attend a transition program located about an hour away from home. It was important to Sarah, her family, and many in her community that she stay in the community she had worked hard to establish.

With the help of advocates who facilitated open communication, the team was able to reach an agreement that centered on supporting Sarah in her long-established community. Sarah will be attending the transition program located



Jim, Sarah, and Rita DeWeese

on the same campus and with the same friends she's known since the first grade.

Community Pathways,
Inc. brokerage was
instrumental in helping to
coordinate services that
support Sarah beyond what
the school could provide...

When Sarah turned 18, she became eligible for brokerage support services

Continued on page 14

and was quickly connected with a brokerage in her area. Community Pathways, Inc. brokerage was instrumental in helping to coordinate services that support Sarah beyond what the school could provide, and they helped find opportunities for her to get even more involved. With the funding she receives from the brokerage, Sarah hires a skills trainer to assist her in a volunteer position close to home at The Pearl at Kruse Way, a senior care community.

Hiring a skills trainer who knows Sarah and her communication style has been key in helping her be successful in her volunteer position.

As a result, Sarah now volunteers two days a week. She has become an important team member, contributing not only physical assistance but also enhancing the positive atmosphere for the senior residents.

"Sarah's diagnosis is Angelman Syndrome and she truly is an angel," says her mother, Rita. "One characteristic of Angelman is that they are typically extremely happy. Sarah's favorite part of her job is to spread that joy as a companion for the retirement community residents. After all, laughter is often the best medicine." Everyone at "The Pearl" knows Sarah, and as she begins her shift, she is greeted by staff and residents. Sarah's primary responsibilities include assisting residents who use wheelchairs in getting to and from the dining hall during a weekly culinary event, feeding the fish in the center's two aquariums, and interacting with the residents. She sometimes entertains the residents by playing "oldies" from her iPod or playing games and puzzles with them.

Volunteering at The Pearl has been beneficial for Sarah as well as the residents. This position has helped to build her self esteem. Her skills trainer, Katie Corrigan, who has known Sarah for many years, has noticed a big change in her. "She did experience some anxiety when she started in this position," says Katie. "It took time for her to learn what was expected, get to know the residents, and for them to get to know her."

Hiring a skill trainer who knows Sarah and her communication style has been key in helping her be successful in her volunteer position. She has difficulty with verbal communication and is using a communication device with pre-programmed, commonly used expressions and responses. Katie also helps Sarah follow her schedule while at her volunteer job.

Through collaboration and brokerage services, Sarah is on a solid path toward an active and meaningful life after high school. Her increased skills, self-esteem, and social connections will serve her well as she takes her place as an adult in her community.



A Little Help Makes Active

Living Possible

When Kristin Burden finished school, those closest to her weren't at all sure what was in store for her.

Kristin is a bright, bubbly young woman who has developmental disabilities. Fortunately, Kristin now receives services from Resource Connections of Oregon (RCO), a service brokerage that helps support her to live independently in her own apartment. She is actively involved in Special Olympics, volunteering in her community, and has worked as a courtesy clerk at Safeway for the past 6 years.

Kaye Burden is Kristin's aunt and guardian, as well as her biggest fan and supporter. According to Kaye, "The brokerage has been a life saver. Kristin is very fortunate to have a job and a support system in place." Her personal agent, Bill Cummins, has been effective in connecting Kristin to appropriate services and building a good rapport with her, as he tries to do with all his customers. Kaye feels that Bill not only ensures that Kristin has all the necessary supports she needs, but he also works to break down barriers in the community for people with developmental disabilities.

During the transition into her own apartment, Kaye was hired as Kristin's in-home support provider. As Kristin got comfortable being on her own, she hired two other providers, both of whom she



Kristin and Kaye Burden

had known through Special Olympics. Kristin and Kaye felt it was important that they hire people who knew Kristin and were patient and understanding.

One of her employees mainly provides assistance with independent living skills, such as budgeting and grocery shopping. Kristin works with the other provider to find things to do in the community, like going to the community center, the coast, hiking trips, and concerts. Getting out and staying active are high priorities for Kristin and made possible because of the supports she receives. Kristin uses public transportation to get around Salem, including Cherry Lift, a service provided for people with disabilities.

Kristin's story demonstrates that a young woman with developmental disabilities can, with a little extra support, be independent, make choices, and stay active in her community.



Creativity Builds Road to Employment

Several years ago, Beau Bullock's efforts to find employment came to a dead end. Even with assistance from his local Office of Vocational Rehabilitation (VR), Beau was not able to find a job, and his VR case was closed. But recently, through good old-fashioned community networking, his personal agent at Resource Connections of Oregon (RCO) brokerage helped Beau land a volunteer position with a local business as an information technology intern.

Sunny Farley is a lead personal agent with RCO brokerage, which is housed in the same building as Linn-Benton Mediation Services, a private non-profit organization that provides alternative dispute resolution services. Sunny discovered that the executive director of Linn-Benton Mediation Services, Miriam Bautista, was interested in expanding the diversity of their workforce, including employing people with disabilities. Sunny had assisted with the development of Beau's person-centered plan, and she was familiar with his strengths and interests. She approached Miriam with the idea of carving out a position for Beau, and together they designed an internship that allows him to use his computer and administrative skills as well as provide opportunities for him to grow and learn in other areas.

As an intern, Beau has become part of the team. He provides technical support to the staff with computer programs such as Dreamweaver, a program used for developing and updating websites. He has his own desk and workspace and regularly attends staff meetings. Beau has difficulty hearing, but he is skilled at reading lips. His co-workers have learned to look directly at him and slow down when speaking. Some of the people he works with are familiar with the American Sign Language (ASL) alphabet, and they spell out words to communicate with him.

This position has been a successful match for Beau, and it has a good chance of leading to paid work opportunities. Linn-Benton Mediation Services is sponsoring Beau to attend classes at Lane Community College (LCC). "Once Beau is finished with the program at LCC, we hope to hire him on," says Miriam. When asked what he likes best about his internship, Beau replies, "I like helping other people with their work goals." And with a little luck and continuing support from the brokerage, Beau might be able to reach his own goal of having a real job.



Still Young at Heart

Roxy Dollar is 86 years old but still young at heart. She loves music and dancing. Once, she attended a concert downtown and said, "I had to show those people how to dance!"

Roxy lives on her own in north Portland. She's a dedicated volunteer at the Northeast Emergency Food Program, which operates out of the basement of her church, Luther Memorial. Roxy is very proud of her volunteer job. She sits at the front desk and makes sure people sign the list as they enter. Her outgoing personality and keen sense of humor help put people at ease immediately. If they are new to the program, Roxy explains what they need to do. Her co-worker Jenny says, "Roxy adds a positive element to what we do here. When she isn't here, people will ask, 'Where is the lady who usually sits at the desk up front – you know, the one who makes us laugh?""

When Roxy was very young, she was placed at Fairview Training Center due to her developmental disability. Her biological mother rarely came to visit her, but a family from her neighborhood used to visit her often. When she turned eighteen, Roxy moved out of Fairview and lived with these same neighbors, who considered her family.



Roxy Dollar at her volunteer position

As the other children in the family grew up and left the house, Roxy felt it was time for her to be out on her own, too. For several years, she lived on her own with drop-in support from family and church friends. As Roxy aged, however, her health and living situation began to decline, and it was evident that she needed more support. She was living in an apartment that had developed a mold problem. The mold contributed to

The support Roxy receives from Inclusion Inc. is not substantial, but the impact is huge.

frequent upper respiratory infections, which led to several trips to the hospital. Also, Roxy had been a regular member of Matt Dishman Community Center in

north Portland and used to swim at the pool independently. Unfortunately, her arthritis got so bad that she fell at the pool, and the staff at Dishman began to fear for her safety. They told her that she could no longer go to the pool without an attendant. She was forced to stop going because she didn't have anyone to go with her. Roxy became very isolated and spent most of her day watching T.V. in her apartment.

Once she was enrolled in Inclusion Inc. brokerage support services, Roxy's life improved dramatically. Staff helped her move into a new apartment and hire someone to assist her few days a week. Roxy's provider, Mary Lewis, has been

with her about four years now. She helps Roxy make a grocery list every week, go to the bank to cash her check, and clean her apartment. Roxy cooks some meals using the microwave or stovetop, but Mary helps with more involved meals that require the oven. Mary also provides support during medical appointments and helps Roxy get her medications. And Roxy is able to go back to Dishman pool now that Mary can go with her.

The support Roxy receives from Inclusion Inc. is not substantial, but the impact is huge. Thanks to brokerage supports, Roxy can continue living independently and safely in her own apartment in her community.



From Isolation to Engagement: Jessica's Story

At the end of the 2009 school year, Jessica Justice and her mom, Cindy, were in for a surprise. They had counted on Jessica attending the transition program for one more year, but because her birthday is in August, they found out she was no longer eligible to continue going to school.

With such short notice, they were left scrambling to piece things together so Jessica could have the supports she needed throughout the day. It was not safe for Jessica to be at home by herself, so Cindy had to take a leave of absence from work to care for her. Without the structure she was used to or anything to occupy her



Jessica Justice

time, Jessica spent all of her time at home, except for an occasional trip to the store or mall with her mother. She became depressed and got to the point where she wouldn't even leave her room. Cindy went through all the formal channels, starting with Jessica's county case manager, to try to get the supports she needed for her daughter. It took several months, but eventually Jessica was enrolled in Community Pathways, Inc. brokerage.

"Jessica is a totally different person now..."

Cindy has been very impressed with the ongoing support they receive from Jessica's personal agent, Arlen Bynum. He always comes out to the house when they need to meet, and he resolves problems quickly. For example, together they decided that Jessica would benefit from having a behavior specialist come to the house and work with her, get her motivated to get out of her room, and find things that she liked to do. The first behavior specialist they hired was not a good fit for Jessica. Cindy called Arlen and within a day he had someone else for them to interview. The second behavior specialist turned out to be a great match. She really knew how to work with Jessica, who is doing so well now that she no longer needs this type of support. Instead, she uses her brokerage dollars for other things that are important to her.

Arlen also helped Jessica find an agency that would help her develop employment

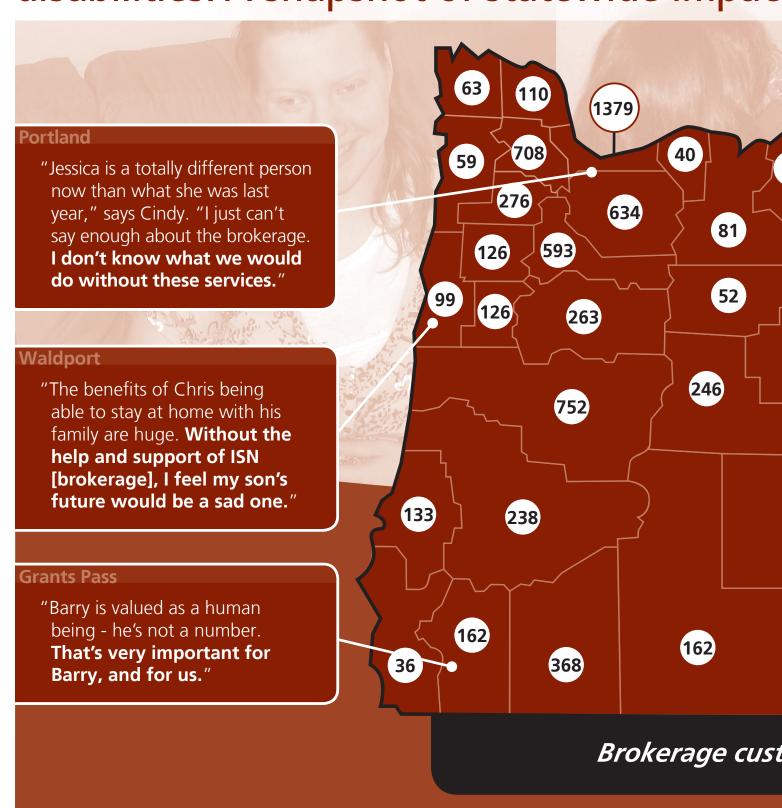
skills. He arranged several interviews with agencies that specialize in helping people with disabilities find employment. Jessica decided to work at Goodwill Industries. She now enjoys working three days a week in a warehouse. The job allows her to earn money and have opportunities to get out in the community. Jessica uses some of her brokerage dollars to buy a monthly Trimet Lift pass, the public transportation service that she takes to and from work.

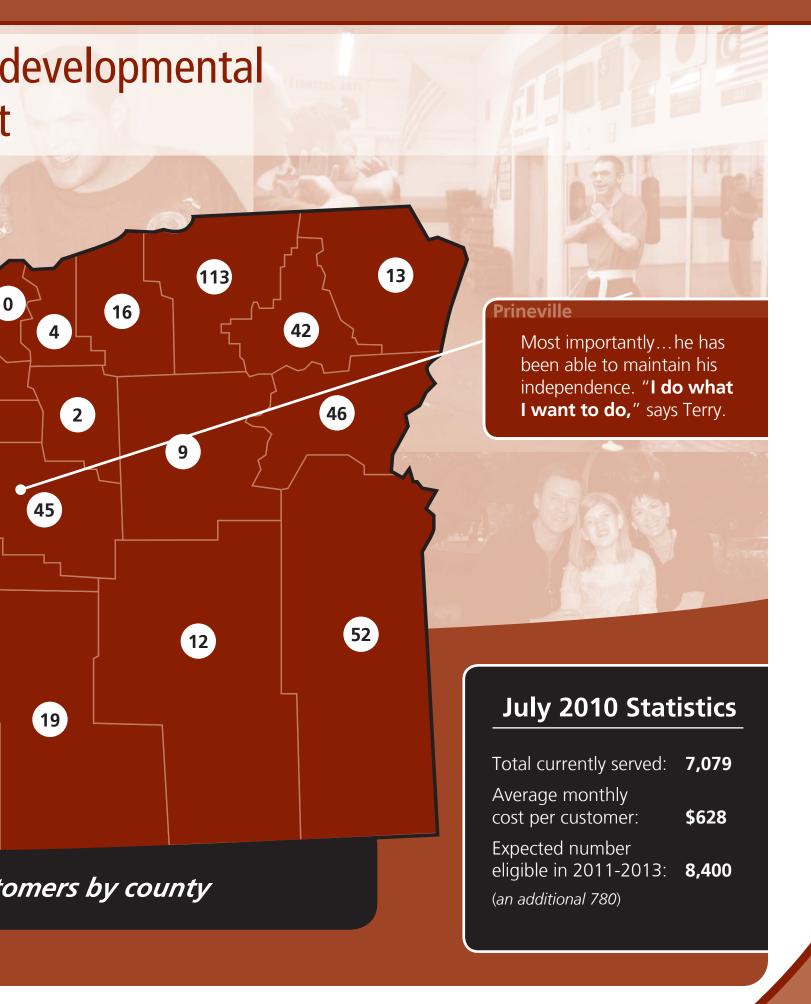
Jessica is very shy and rarely talks when she is introduced to new people or is in a new environment. However, now her supervisor at Goodwill reports that she is too social! Her favorite day is payday, and she is saving up to buy a computer.

On the days she does not go to Goodwill, Jessica has a care provider who works with her on cleaning and cooking meals. They also find activities in the community, such as going shopping, to the movies, and to the zoo. Jessica and Cindy interviewed people for this position from a list of quality providers maintained by the brokerage. They have been very pleased with the provider they hired. She has built a good relationship with Jessica and helps her think about things she could do in the community.

"Jessica is a totally different person now than what she was last year," says Cindy. "I just can't say enough about the brokerage. I don't know what we would do without these services. I have to work. I can't just stay home. I wish that we would have known about these services earlier and didn't have to go through what we did last year."

Brokerage support services for adults with disabilities: A snapshot of statewide impact







The New Sue

Susan Berg, a young woman with developmental disabilities, had anxiety and depression and spent most days isolated in her apartment. Many of the residents at Susan's apartment complex have lived there for years, and they are like family to her. She often relied on them for support, but it was never enough. "The brokerage program has been amazing," says Ella Huggins, her longtime neighbor and friend. "Before Susan got any of these services, I helped her with everything. I brought her groceries and helped her manage her money." Ella is now Susan's designated representative payee and continues to help her with her finances.

It was Susan's county case manager who suggested that she could benefit from brokerage services and referred Susan to Independence Northwest brokerage. Once she was enrolled, Jessica Kral, a personal agent with the brokerage, came to Susan's house, and they talked about the types of support Susan wanted and needed. Together they developed a plan for her. Then Jessica helped Susan interview a skills trainer who could assist her a few days a week and also connected her with Caroline Kobin, a behavior support specialist and certified life coach. Since working with Caroline, things have gotten much



Susan Berg and her cat, T.J.

better for Susan. "Caroline was able to help me with what I was going through," Susan said.

Susan desperately needed help cleaning her apartment. Part of the problem was that she wouldn't throw anything out. "I was a hoarder, like on those T.V. shows," Susan says. The brokerage helped her hire a professional cleaning company to "deep clean" her apartment.

"When I met Sue...she had not left her apartment complex in four years."

Now that she has a skills trainer, Susan is better able to take care of her apartment. Her skills trainer, Jill Campoli, also helps Susan get out and do things in the community, which has been a big change for her. According to Jessica,

"When I met Sue in September of 2008, she had not left her apartment complex in four years. Ella ensured that Sue's basic needs were being met, but Sue's disability, combined with her anxiety, prevented her from getting out into the community. In the last year and half Sue has been able to go to medical appointments, grocery shopping, movies, and other activities in the community. It's been an amazing transformation."

Susan looks forward to getting out and doing other things, too, such as hiking or taking a trip to the coast. She is connected with a church group that reaches out to members of the congregation when they need it. People at Susan's church have definitely noticed a difference in her. She says proudly, "They call me 'the new Sue.'"



Support Services Help Customer Deal with Depression and Stress

About a year ago, Coral Doran, a young woman with developmental disabilities and a mental health disorder, had become isolated and depressed. She was frequently hospitalized due to severe emotional distress. Since Coral enrolled in the Self-Determination Resources, Inc. (SDRI) brokerage and started getting the services she needed, she has gone from frequent hospitalizations to being an active, contributing community member who feels good about her life.

Coral lives with her mother, and when things start to get difficult for Coral, they both benefit from having some time



Coral Doran and her personal agent, Kelly Blanton-Duffield

apart. Kelly Blanton-Duffield, her personal agent at SDRI, connected Coral with a respite care provider, Aster Mohammed, who is a licensed foster care provider for adults with developmental disabilities. Aster has one room designated for temporary respite care, and Coral can stay there when she feels overwhelmed or needs to have her medication adjusted. When Coral begins to feel stressed, she can request to stay in respite care for up to a week, and this is built in to her brokerage budget. Coral and Aster have developed a trusting relationship, and Coral feels comfortable at Aster's home. "Aster is really great to talk to," says Coral. Having access to this type of support has helped tremendously, and Coral feels that it has kept her out of the hospital for over a year.

She was frequently hospitalized due to severe emotional distress.

Coral also needs support to be more active and reduce her isolation. Kelly helped Coral interview and hire Julia, who is a skills trainer. With her brokerage dollars, Coral meets with Julia two to three times a week, and she says, "I really liked Julia from day one." They find fun, affordable things to do together such as visiting local libraries, museums, and gardens. Julia also provides assistance with medical appointments.

In addition to regular outings, Coral works two days a week as a janitor at

a local senior center. She also takes pride in her position as a volunteer with the local food bank and with the Meals on Wheels program; both positions offer Coral a chance to give back to her community and be seen as a contributing community member.

She used to be afraid of taking the bus, but after working with her skills trainer, she is now able to ride the bus independently and do things on her own.

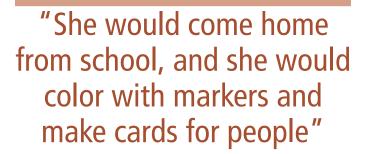
The brokerage helps Coral purchase a bus pass. She used to be afraid of taking the bus, but after working with her skills trainer, she is now able to ride the bus independently and do things on her own.

Coral's story is truly a success story. With a little added support, she has gone from isolation and frequent hospitalizations to being in control of her life, more independent, and actively involved in her community.



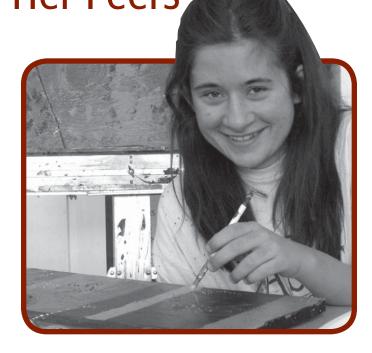
Award Winning Artist Once Shunned by Her Peers

Mieke Ryneal's accomplishments are extraordinary, but things have not always been easy for this young woman who has disabilities. Mieke's mother, Charlene Ryneal, says, "At school she was often teased, called names, and shunned by her peers. She would come home from school, and she would color with markers and make cards for people, because she wanted to make them happy. As her parent, it was heartbreaking to see my child be so rejected, yet be so giving."



Mieke started going to The Studio at Living Opportunities, an art studio for people with developmental disabilities. Living Opportunities, Inc. is a non-profit organization located in Medford that provides residential, vocational, and recreational supports to people with developmental disabilities. A generous donor paid the hourly fee so that Mieke could attend.

Mieke and Charlene attended a Dream Café in Medford, where they learned about Creative Supports, Inc. brokerage.



Mieke Ryneal at The Studio at Living Opportunities

Creative Supports hosts Dream Cafés in order to connect parents and people with developmental disabilities with existing resources. There Charlene learned about special needs trusts, employment opportunities, and brokerage support services.

Mieke applied for brokerage services when she turned eighteen. Charlene explains, "Connecting with the brokerage at that time was crucial in order for Mieke to continue going to The Studio because the donor funding was going to run out." They were thrilled to find out that Mieke could use her brokerage dollars to pursue her love of art and continue going to The Studio, where she felt comfortable and had become part of the community.

Continued on page 26

The artists and volunteers at The Studio are encouraging and supportive. Since Mieke has been going there, she has grown as an artist and has gained the confidence to try new things, like developing her own painting technique. Paintings are displayed in the gallery next door, and visitors to the gallery will often

The awards banquet was held on Capitol Hill in a congressional office building. U.S. Senators and Representatives were in attendance. The president of VSA presented the certificates and award checks. One of her winning pieces was on display in the Smithsonian, and the other was displayed in the John F.

"I just couldn't believe it! This is the most exciting thing that has ever happened to me," says Mieke."

stop by The Studio to see the artists at work. Sometimes, when people see one of Mieke's paintings in progress, they want to buy it as soon as it is finished.

The Studio's art director, Dan Mish, helped Mieke enter a national competition for artists with disabilities ages 16-25. One day, Mieke received a call from the sponsor of the competition, VSA International Organization on Arts and Disability, to inform her that two of the paintings she submitted had won. At first Mieke had difficulty understanding, but once she realized that she had won, she started screaming with joy. "I just couldn't believe it! This is the most exciting thing that has ever happened to me," says Mieke. Two days later she received an email telling her that she, along with eleven other winners, would be traveling to Washington, D.C., to receive her award, all expenses paid. She exclaims, "This was my first time on an airplane. I had never been to the east coast. I couldn't believe I was going to Washington, D.C."

Kennedy Center for the Performing Arts. "I was just in awe to be able to show my painting in such an incredible place. I didn't want to leave," Mieke says with a laugh.

The exhibit is also on a nationwide tour and is being presented in galleries across the country. Her certificate now hangs on the wall of their living room.

Charlene says, "We couldn't afford to send Mieke to The Studio, so we've been especially grateful for the help we've gotten from the brokerage." A fairly small amount of money is making a huge difference in Mieke's life by helping her develop her talent, her confidence, and her connection with her community.



From Growing Isolation to Inclusion: Dana's Story

As a young girl, Dana Shipman was diagnosed with developmental disabilities. In those days, parents were often advised to place a child like Dana in an institution. Her parents, however, did not follow the professionals' advice. They felt strongly that Dana should remain at home with her family. For most of Dana's life, her family provided all of her daily care without the help of any formal support services.

They grew concerned about the isolating effect this was having on their daughter.

Her parents, Pat and Keith Shipman, are now in their late 80's and don't drive much anymore. They grew concerned about the isolating effect this was having on their daughter. They decided to enroll Dana in the support services brokerage, Full Access, to get the supports Dana needed to stay active and build relationships in the community.

Dana uses her brokerage dollars to hire Debbie Rutkai, a provider who assists Dana in finding things of interest to her. "Debbie has been an absolute jewel," says Pat. Debbie works with Dana two



Dana Shipman getting her hair styled

days a week, and they have developed a strong relationship. "We always have a great time," says Debbie. "Dana is tons of fun to be with!" According to Mia Swanson, Dana's personal agent at Full Access, "Working with an inclusion provider has really opened and expanded Dana's world and made a huge difference in her life."

It is important to Dana and her family that she has opportunities to exercise regularly. Every Tuesday, Dana and Debbie go to the Juniper Swim and Fitness Center where Dana uses the exercise room, does water aerobics, and finishes with a soak in the hot tub. On their other day together, they do things

Continued on page 28

like going out to eat, walking, shopping, or visiting the hair salon so Dana can get her hair styled.

...people in the community are becoming familiar with Dana and are learning how to communicate with her.

Now that they have built a trusting relationship, Dana is sometimes willing to try new activities that Debbie introduces, such as line dancing and concerts in the park. But Dana lets it be known when she doesn't like something. For instance, Debbie quickly discovered that bowling is not something Dana is interested in trying. Dana primarily communicates through vocalizations and facial expressions, and as soon as they

walked into the bowling alley, Dana made a very disapproving face. Through this process of trial and error, Debbie helps Dana explore new options and make choices.

The best part of this consistent routine has been that people in the community are becoming familiar with Dana and are learning how to communicate with her. Debbie helps facilitate communication with others by "filling in the story" and explaining what Dana has been up to. Dana loves to carry things with her to share with others, such as a stuffed animal or jewelry.

According to Pat, the services they receive from the brokerage have been extremely important. "This is a real service for elderly parents caring for their adult children with disabilities, especially because of our health issues," says Pat. "This has been the greatest thing that could ever happen to us."



Independence is Preserved with Community and Brokerage Supports

Up until a few years ago, Terry Hilgers lived in a house in Prineville with his girlfriend and other roommates. Unfortunately his girlfriend passed away, and soon after that Terry's living situation deteriorated. His utilities were going to be shut off because he didn't pay the bills.

He didn't like to spend time at the house with nothing else to do, so he would often wander the streets. Terry, an older adult with developmental disabilities, had reached the point of crisis. He urgently needed support to move into a better living situation.

Terry was already connected with Full Access, a support services brokerage. He called Ashley Cary, his personal agent, to let her know things had changed. She immediately helped him secure a new apartment in a complex that he liked because he knew some people who lived there. She also began to coordinate supports to assist Terry to live safely on his own. Since then, things have turned around for him, and he is now doing much better.

...he would often wander the streets.

Terry's is a familiar face in Prineville; everyone in town knows him. Members of this small central Oregon community have helped him get established in his new apartment. A generous local couple, who were moving out of state and were planning to give much of their furniture away, donated it directly to Terry and even helped deliver it to his new apartment. Now he has a couch, bed, chair, coffee table, kitchen table, and other kitchen items.

With part of his brokerage budget, Terry hired a provider, Audra Troutman, to help him a few days a week with cleaning, shopping, cooking, budgeting, and planning. In addition, she helps him fill out important forms and paperwork, such as for Supplemental Security Income (SSI), and she provides transportation to medical appointments in Bend. For fun, they go shopping and to different community events. Terry is a big fan of classic movies. He likes to shop for movies with stars such as John Wayne, Kurt Douglas, Marilyn Monroe, and Burt Lancaster.

The brokerage also purchases a bus pass for Terry so he is able to use Dial-a-Ride, an accessible transportation service for people with disabilities.

With the supports he receives through the brokerage, Terry is now safe and happy in his new apartment in the community he knows and loves. Most importantly for Terry, he has been able to maintain his independence. "I do what I want to do," says Terry.



From a Downward Spiral to a Future Full of Possibilities

After graduating from high school in Florida, Barry Boston did not have a clear path for his future. Due to his disability, Barry has difficulty with assessing risk, and according to his uncle, Jim Boston, "he began filling his time hanging out with the wrong crowd." Barry's life was in a downward spiral. People in his social circle were taking advantage of him, and their influence was leading Barry to make bad choices. When things finally reached a critical point about a year and a half ago, Barry moved to Oregon to live with his Uncle Jim and Aunt Pam.

Jim and Pam worked to add structure to his life and find Barry the supports he needed. "The goal is for Barry is to learn to structure his own life," says Jim. The Bostons heard about brokerage services through a friend, and when Barry came to live with them they started applying for support services through the county. "It was a multi-step process. It took about six months, but we are very grateful for the services he receives now."

Dana Pearce, Barry's personal agent at Creative Supports, Inc. brokerage in southern Oregon, has used a variety of techniques and tools to help Barry explore possibilities for his future, based on his strengths and interests. Going through a person-centered planning process was something Barry had never done. Focusing on what he is good at and enjoys doing has had a positive



Barry Boston getting his first belt in Kung Fu

effect on his self confidence. "Dana is a fountain of information and resources. She is obviously interested in Barry's success, and he is comfortable with her. Barry is valued as a human being - he's not a number. That's very important for Barry, and for us," says Pam.

Based on Barry's desire to find employment, Dana helped connect him with Vocational Rehabilitation and a job developer. Now Barry volunteers five days a week for the after school program at Boys & Girls Club and is gaining job skills. He plays games with the kids, keeps them on task, and keeps a watchful eye on the kids' safety. Barry also spends one day a week working at the YMCA. Since one of Barry's favorite hobbies is rock climbing, he works as a belayer – controlling the rope for climbers on the indoor rock wall. Climbers have to trust him in this role. He

also works with a partner to help keep the YMCA clean and looking great.

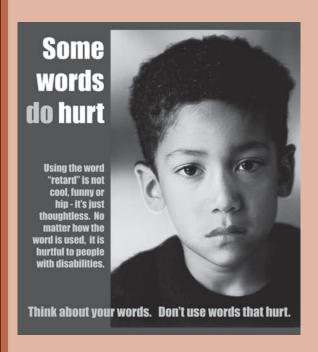
"Creative Supports has been a tremendous help," says Jim. In addition to the supports for Barry, Jim and Pam receive mileage reimbursement for providing transportation for Barry. The brokerage also assists with paying for respite care when Pam and Jim go out of town, since Barry is not yet able to stay by himself for long periods of time.

Barry's goal is to live independently and have his own place with a roommate. He has learned to do his laundry and is working on cooking skills and kitchen safety. Through the supports he receives from his family and that of the brokerage, Barry has turned his life around and is looking forward to a bright future full of possibilities.



Barry belaying for climbers on the rock wall

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News and Views from the Oregon Council on Developmental Disabilities

New ADD Commissioner, Sharon Lewis



Sharon Lewis, who has roots in Oregon, was appointed in the spring by President Obama to lead the Administration on Developmental

Disabilities (ADD), which is the federal agency that oversees State Councils on Developmental Disabilities and other programs across the country. Commissioner Lewis, the parent of a child with a disability, began her career in advocacy as a graduate of the Oregon Partners in Policymaking program. She quickly became a driving force in several grassroots advocacy efforts in Oregon including Multnomah Parent Action Committee (MPAC), Family and Community Together (FACT), development of the Oregon Disability Network, and coordinator

for the Council's Partners in Policymaking program. In 2007, she received the Joseph P. Kennedy, Jr. Public Policy Fellowship and has been in Washington, D.C. ever since. She went to work at the U.S. Capitol as the House Education & Labor Committee's Senior Disability Policy Advisor. In April, 2010, she received the Leadership in Disability Policy Award from the top national developmental disability advocacy organizations for her accomplishments in this position, which included work on the ADA Amendments Act, the Individuals with Disabilities Education Act, the Higher Education Opportunity Act, and the Keeping All Students Safe Act, a bill that limits the use of seclusion and restraints in public schools.

Western States DD Collaborative Summit

In May, the Council hosted a two-day Western States Summit in Portland for the ADD network partners, which consist of DD Councils, Protection & Advocacy Agencies, and University Centers for Excellence in Developmental Disabilities. In addition to Oregon, agencies from Washington,

Idaho, California, Nevada, and Alaska were represented. The theme of the summit was collaboration and building a sustainable future for developmental disability services.

A Decade of Accomplishments

he Council and the Oregon **Developmental Disabilities Coalition** sponsored an event at the Capitol on February 24th to celebrate all that was accomplished during the last decade, including the closure of Fairview Training Center in 2000, the creation of Support Services for Adults, and the closure of Eastern Oregon Training Center (EOTC), Oregon's last remaining institution for people with developmental disabilities. Over 300 people attended the celebration, which included a proclamation from the Governor, remarks from influential advocates, and the unveiling of this year's awareness poster. The theme for the awareness poster, co-produced with The Arc of Oregon, was "With Good Planning and Support, Everyone Can Work." Annual DD Champion awards were presented to former EOTC Superintendent Bob Clabby

and staff for their successful transition of the last residents at EOTC, and to parent advocates Jan Schroth and Katherine Palmer, both of whom are parents of children with



Bill Lynch, Gayle B. Gardner, and DD Champion Award winners Jan Schroth and Katherine Palmer

developmental disabilities and served on the EOTC Review Board. The Oregon DD Coalition presented awards to James Toews, Assistant Director of Seniors & People with Disabilities Division, and Mary lee Fay, Administrator of the Developmental Disability Program. They were recognized for their longstanding leadership and dedication to people with developmental disabilities in Oregon.



Council Director Plans to Retire

In July, our Executive Director, Bill Lynch, announced that he is ready to begin a

new chapter in his life. After 16 years as a member of Council staff (including the last 7 as our executive director), he submitted his resignation, effective December 31, 2010.

Bill has led the Council through good times and challenging times. Under his leadership, we have accomplished much in our state and around the nation. He has been a remarkable advocate, champion, and leader, helping us hold our vision and cling to our values as we work toward positive change in the lives of people with developmental disabilities and their families. To say he will be missed is a real understatement. We send Bill into his retirement with love and gratitude for his many years of service. While we are happy that he will have time to pursue new and exciting opportunities in his life (including travel and consulting), part of our hearts go with him as he begins the next, still to be written, chapter in his life.



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Members of the Oregon Disability Network receive information, *Oregon Perspectives* and other publications, learn about training opportunities and events, and have the chance to voice their opinions on policy issues at the local, state, and national levels. To join, contact the Council or visit our website at ocdd.org to download a copy of the sign-up form.

Already a member of the Network? Update your email address with us and receive GO! Bulletins, alerts, and electronic versions of publications.

On the left: 2010 DD Awareness Poster produced by the Oregon Council on Developmental Disabilities and The Arc of Oregon. "With Good Planning and Support, Everyone Can Work." For a free copy, contact the Council at 503-945-9941 or e-mail: ocdd@ocdd.org