

STEPPING UP

Winter 2015

Issue 23



PUBLISHED BY THE NORTHWEST DOWN SYNDROME ASSOCIATION
CELEBRATING EVERY PERSON WITH A DISABILITY, INCLUDING DOWN SYNDROME

INSIDE THIS ISSUE

- 1 College Within Reach
- 1 Celebration
- 2 Letter from the Board
- 3 Spanish Piece
- 4 World DS Day
- 6 All Born (in) Wrap-up
- 8 Buddy Walk Wrap-up
- 10 Open Arms Returns
- 10 Bike Week
- 11 DS Awareness Month
- 12 KIC Session Underway
- 12 DRO Legal Victory
- 12 25 Years of the ADA
- 13 End of the Year Gift
- 13 TASH Conference
- 15 Toast to Inclusion
- 15 Voter Ambassadors
- 15 Calendar of Events

College within reach for Oregonians with intellectual disabilities

For the first time in Oregon, individuals with intellectual disabilities will have access to an inclusive postsecondary education at a four-year university, thanks to the efforts of Think College Inclusion Oregon, Northwest Down Syndrome Association/All Born (in), and Portland State University. A \$2.5 million, five-year grant from the US Department of Education will fund a college program at Portland State University facilitating the enrollment of students with intellectual disabilities which will better prepare them for eventual employment and adult life within their community.

While Portland Public Schools' existing Community Transition Program has provided much-needed services and resources for 18-21 year-olds for over two decades, the \$2.5 million grant allows for expansions to the program that will enable students to receive a more immersive and inclusive college experience alongside their peers.

Please see *College* on page 5

Celebration: "All this work has come to something good"

By Abby Braithwaite

Edie Brown was a woman on a mission. In the words of her son Ken, she was "a collector of righteous causes that needed someone to fight them." When her youngest son Eric was born in 1976, she found herself with one of the greatest "causes" of her long, full life sitting right on her lap. Eric was the youngest of seven children, and when Edie and her husband David brought him home from St. Vincent's hospital, they quickly realized that their busy household was the perfect place to raise a child with Down syndrome. With six older siblings to play with him and teach him all they knew, he was surrounded by all the right kinds of stimulation, and his sister Christina, especially, took him under her wing. Eric and Christina were tied at the hip. Christina loved teaching her little brother anything and everything—sucking out of a straw, tying shoes, doing summersaults, and reading books.

But Edie also quickly realized that in 1976, society didn't have much space for a child with Down syndrome, and she was appalled to realize how poorly her son and his peers could be treated, how low expectations were, and how few opportunities there were for him to learn and thrive. Things were going to be different in the Brown family, and so began a long life of advocacy.

Edie connected with other forward-thinking parents through PRIDE for kids, an organization founded by Judy Marick and Kay Parks, both moms of young sons with Down syndrome, in conjunction with early childhood educators and researchers at the University of Washington.

Please see *Celebration* on page 14



NWDSA

northwest down syndrome association

Resourcefulness Center
11611 NE Ainsworth Circle, Ste 321
Portland, OR 97220

Mailing Address
PO Box 9127
Portland, OR 97207
www.nwdsa.org
www.allbornin.org
503-238-0522

Stepping Up is published quarterly by the Northwest Down Syndrome Association (NWDSA), a non-profit organization managed by a board of volunteers.

To be added to our mailing list visit www.nwdsa.org or send your mailing info to the address above. There is no subscription fee, but if you would like to make a donation, you may send a tax deductible contribution to the NWDSA at the address listed above or use PayPal on our website.

Readers are welcome to submit letters and articles to the address above or e-mail abraithwaite@nwdsa.org. Please include your name, address, phone number and e-mail. All submissions will be reviewed and edited for content and style.

The NWDSA Mission:

Create and nurture a loving and inclusive community celebrating every person with a disability, including Down syndrome.

The NWDSA will accomplish this mission by empowering and supporting families and individuals who have been touched by Down syndrome. We will work to increase education, promote public understanding and acceptance, and toward full inclusion of individuals with Down syndrome in our community.

Opinions published in *Stepping Up* are not necessarily those of the NWDSA

Dear families and friends of the NWDSA

By Steve Holland, NWDSA President

Happy Holidays to the entire NWDSA community. Thank you for being a part of our lives this past year, whether you have joined us at a social or a workshop, learned with at the All Born (In) conference, or walked with us at Buddy Walk. Whatever your connection, we are glad to have you alongside.

Looking back over the past year, I can genuinely say that I serve with some of the most dedicated, passionate folks I have ever met. Whether Board Members, staff members or partners in the community, the people affiliated with NWDSA/ABI are truly committed to a shared mission of creating a more inclusive world.

In a first-of-its kind session on policy at the 2015 All Born (In) Conference, family members, teachers, administrators, self-advocates and policymakers came together to create a shared vision around policy that will lead to more equity in our schools and communities. The session was facilitated by Sara Drinkwater from the Oregon Department of Ed and Krista Flint from Inclusive Humanity, and was captured in real time by graphic facilitator Aniko Adany from OTAC.



It was a great process, and the representation hangs on the wall at the NWDSA/ABI Resourcefulness Center to help keep that directive present in everyone's minds as we do our work together.

The NWDSA Board of Directors carried the charge from that session into our regular board retreat in June, as well as to our strategic planning retreat in September, and we worked diligently with our facilitator, Krista Flint, to create a 3-year strategic plan for our organization. We were supported in the planning process by a grant



from the Meyer Memorial Trust, and it was a great opportunity to take some extra time as a board to look past our annual work plan and dig in to our long-term vision, as well as our sustainability as an organization.

We enjoyed some new faces in the office this summer. Two incredible volunteers, Alison Schneiger and Jamie Jones, helped shape the strategic plan, as well as helping with grant-writing and Buddy Walk. Summerworks staffers Palace Chalfa and Rachel Esteve brought youthful energy and enthusiasm to new parent outreach and event organization and procurement. We are delighted to have Rachel continuing to work with us one day a week. We are also in the process of bringing some new staff members onto the team.

Thank you again for being a part of the NWDSA/ABI community. I look forward to connecting with you in the year to come.

Creando conciencia en nuestra comunidad

By Maria Rangel

Pienso que el programa de alcance para familias Hispans/Latinas es muy importante, ya que así las nuevas familias se conectan a servicios, participan en grupos de apoyo, conocen a otras familias, crean una red de amigos/as, y reciben información mediante entrenamientos y conferencias. Sin programas como estos, nada de eso sería posible; así que organizaciones como esta trabajan y se esfuerzan muy duro para lograr todo lo que se pueda.

Considero mi trabajo muy importante pero a la vez un poco difícil. En la comunidad Hispana/Latina las discapacidades son vistas de una manera muy diferente a como la discapacidad verdaderamente es, muchas veces porque la gente no está informada y no saben realmente qué es una discapacidad. En mi experiencia propia, cuando estoy alrededor de mi comunidad y la gente me ve con mi hija que experimenta síndrome de Down, me miran raro, murmuran, y cuando sus hijos les preguntan: “¿Que tiene esa niña?” responden: “Ella está ‘malita’”.

Allí es cuando yo entro y les digo, “Mi hija no está ‘malita.’ Ella experimenta síndrome de Down, una discapacidad causada por un cromosoma demás en el cromosoma 21.” Entonces la gente empieza a preguntarme más y a aprender sobre la condición que mi hija tiene.

Claro, eso digo ahora, pero cuando de primero diagnosticaron a mi hija recuerdo que esas miradas y murmuraciones me hirieron profundamente; y al escuchar que decían que mi niña estaba “malita”, eso me hacía aislarme y no querer salir. Mi situación mejoró hasta que me fui informando y conectando a otras familias que al igual que yo tenían niños con discapacidades, y entonces comprendí que no era la única mamá con una niña con una discapacidad. Aprendí más sobre la condición de mi hija, y hoy puedo compartir mi experiencia con otras familias que están donde yo estuve un día: confundida y sin saber qué hacer ni qué pensar.

Por eso creo que juntos como comunidad necesitamos hacer el esfuerzo de informarnos y participar, empezando con nosotros mismos. Luego podemos compartir nuestros conocimientos y experiencias con familiares, amigos y con nuevas familias para así enseñarles que tener un niño con una discapacidad no es algo raro. Si, es diferente, pero ¿Cuál niño es igual? Ninguno - todos son diferentes, todos son únicos, simplemente necesitamos darles el apoyo extra que necesiten y juntos crear conciencia sobre la discapacidad. Así podremos lograr que nuestra comunidad le dé la buena bienvenida a todos los niños sin importar diferencias.

La NWDSA ha sido una red de apoyo de familia dirigido por padres y madres desde 1997. La misión de la NWDSA es de crear y nutrir una comunidad amorosa e inclusiva celebrando cada persona con una discapacidad, incluyendo síndrome de Down. Para comunicarse en español, llame o Isis Sanchez (503) 442-5817 o a Sheyla Hirshon (503) 239-1509.



Maria Rangel (left) and Pamela Dye (right) with Ashley Lawrence from Multnomah Early Childhood Program (MECP), working to expand outreach to new parents of children with disabilities, providing resources such as the New Parent Guide and Heart Booklet to parents of babies diagnosed with Down syndrome. Maria and other volunteers have made great strides in expanding outreach to the Spanish-speaking community, enabling us to offer support and resources to many new parents and families.



Dara (left) volunteered data entry support after the ABI conference. Jasmine (right) helped prepare thank you cards.



Palace and Rachel (left) participated in a summer internship program at the Resourcefulness Center as part of the Work Systems Summerworks Program.

Rachel (right) is now employed at NWDSA, helping in the office and supporting families with young children.

“I am proud of what I am doing, I do home visits to new families and help with Open Arms Play group.” - Rachel



“Next time, we need to provide security for Elsa!” someone quipped as Brandi Shea Frederick, AKA Elsa from the movie Frozen, was mobbed by tiny admirers at the World Down Syndrome Day celebration. After leading the kiddos through a rendition of “Let it Go”, Elsa posed for photos with members of her new entourage.



World Down Syndrome Day Celebration

World Down Syndrome Day (WDS) is observed around the world every year on March 21st (3/21), in recognition of the 3 copies of chromosome 21 that are present in most people living with Down syndrome.

This year we celebrated with a big party in the gymnasium at St. Charles Church in NE Portland. Food, family, games, and music are always part of any NWDSA celebration, but there were a few fun extras – including a live band featuring Newell Briggs and members of IRL, a taco buffet, ice cream sundae bar, DIY button-making station, and a wine and cider bar.

One of the more popular attractions was the photo booth provided by Andrea Hatcher, David Hatcher, and Arly Holzweissig. This fun activity featured hats, costumes, and silly signs. Check our Facebook photo galleries for hundreds of photos from the event at www.facebook.com/nwdsa – find your family, download and share!



College a reality

Continued from page 1

This funding breakthrough is the result of over 2 years of development and vision from Think College Inclusion Oregon—a coalition of middle and high school students, families, education professionals, and PSU faculty—led by NWDSA/ABI.

Although the partners were instrumental in achieving this goal, the real driving force behind the movement is the youth—advocates with intellectual disabilities and without who share a dream of going to college. All of the good work done with Early Intervention in the past couple of decades has produced a generation of young people raised with values of inclusion, equity, and diversity, and the belief that anything is possible with hard work and the right supports. Now that these students are college-age, it's up to families, policymakers, and educators to ensure they have the opportunities they deserve.

Youth advocate Claire B. wrote the following about her family's dreams of college for her and her sister:

"A couple years ago I started hearing about people with disabilities not getting the chance to go to college. Thinking about how silly that sounded I was scared for my sister because we have had such high hopes since we were kids.

From the beginning, Karley and our family [have] been fighting and working for her education, when college comes we will fight for it too. She would learn just like the other students and if needed have a tutor or help just like some of the other students would have. She deserves to have a college experience just like everyone else."

The power of support from parents, families, and allies has been the heart of NWDSA/ABI's mission from the beginning. In the years since forming as a Down syndrome-focused parent group in 1997, NWDSA/ABI has grown to recognize and advocate for the needs of all children with disabilities. Focus has expanded from early intervention during the first five years to encompass a lifespan track, including transition into college years, employment and adulthood. Some other excellent work being done by parents and staff members to create positive change along the lifespan track includes:

Reach 2020: This six-year proposal by PPS Director of Special Education Mary Pearson calls to dissolve the line between general and special education, adopting instead a 'co-teaching' model. NWDSA/ABI Executive Director Angela Jarvis-Holland was quoted in an article in the Portland Tribune: "Part of it is money and part of it really is about attitudes." Read the full article at portlandtribune.com/pt/9-news/246924-114159-pps-plan-would-integrate-special-ed

Please see *College* on page 11



The Reciprocal Learning Community (RLC) provides parents of children aged birth thru five with Down syndrome and other disabilities with much needed tools and strategies to support their success. Recent workshops included "Parents are Best Therapists" with Mary Williams and Ryan Jacobson; and "Shared Reading" with Sam Sennott and Eric Sanders.



"I promised myself I would never push my daughter because I thought she was broken. She is perfect exactly the way she is."
-Shakyrá Rosario opens the session with laughter and a few tears



Thanks to Mindy Parker, Rosa Flores, Anna Herbig, Jenna Botelho Dillon, Abby Braithwaite, Jamie Lesley Burch, Mikki Kellar, Ann Wilson, Dara Huntley, Susan Fleming, Colleen St. Mary, Maria Quinones, and everyone who's helped make RLC workshops successful!

The next RLC workshop is January 16 and the topic is positive behavior supports. Please go to www.nwdsa.org/events for more info.

Annual ABI Conference turns ten

By Abby Braithwaite

On May 2nd, the All Born (In) conference celebrated its 10th birthday, and the cake was delicious. Born in the spring of 2006, the ABI conference started as a gathering of fewer than 100 parents and professionals dedicated to inclusion in schools. Today the movement has grown to include over 2,000 parents, teachers, students, administrators, caregivers, business owners and volunteers, 500 of whom attended the conference.

My daughter Adara was born just a couple of months after the first ABI conference, and we had the privilege of attending for the first time when she was just 9 months old. My husband and I did not quite know what we were doing there, as “inclusion” still seemed like a pretty far-away concept for parents of an infant who was just finding her place in our family, but I am so glad we had the opportunity to attend so early. I will never forget the words of the 2007 keynote speaker Jeff Strully. “If you don’t intend for your child to grow up, graduate from high school, move out, get a job and have a real life,” he asked the room, “what the heck are you doing wasting your time in early intervention?”



And suddenly I got it. ABI is not just about schools, about Special Ed, about getting my kid through school and helping other parents do the same. It’s about the long haul, and about building communities that understand that *All Means All*, that when we take the time to truly embrace and celebrate our differences, we will be the best world. We can share research, tips for success, data and numbers. But at its heart, this conversation about inclusion is really about the human need for belonging. We all do better when we know we belong, when we are supported, and when we embrace the vast array of differences that make up this beautiful human fabric. When we work to best serve a variety of individuals we become better teachers, parents, leaders, and professionals. Inclusion isn’t just about making schools more welcoming for children with disabilities; it is about making the world a richer and more diverse place for everyone.

This past weekend we dropped Adara off at a birthday party for one of her classmates, who had insisted that Adara be on the small guest list. She is included in her school and her life, and embraced by all who know her. This is no accident. As we approach her birthday in the end of June, I am incredible grateful for all that I have learned from being a part of the ABI movement, and am so proud of both my daughter and the ABI movement for a decade of incredible growth and power.





“ When I came home I held [my son] in a different way. Instead of holding him tight I lifted him up!

“ Great ideas and tech resources that I can bring back to my practice in the schools.

“ So many takeaways and aha moments!



All Born (in) 10th Annual Best Practices & Cross-Disability Inclusion Conference

Behavior specialist David Pitonyak started off the day with a thoughtful keynote speech about the importance of belonging and the neurological effects of loneliness. The lunchtime keynote presentation featured a panel of educators and policymakers—Jenny Stonemeier from TASH; Rob Saxton, Deputy Superintendent of Public Instruction in Oregon; and Ricki Sabia from the National Center and State Collaborative—sharing thought-provoking ideas about UDL and their passion for inclusion. The closing speech from self-advocate Eric Matthes ended the conference on an inspiring note about the power of perseverance and support to make employment dreams come true.

Throughout the day were 35 challenging, informative, and empowering workshops ranging from early childhood, through school age and into transition. We were privileged to host so many talented presenters and a wide variety of voices. The theme of this year’s conference—“All Means All”—is a philosophy that’s not only true for children and young adults in schools and communities, but also true for the families, educators, and policymakers who must work together to achieve the vision of a civil inclusive society. The ABI Conference will continue to bring families and professionals together to collaborate and converse for years to come.

Save the date for ABI 2016! Saturday, April 23rd, 2016 at Holiday Inn Portland Airport. Learn more and pre-register at www.nwdsa.org/allbornin



David Pitonyak's presentations were among the highest rated by attendees.

Thanks to our sponsors who make this conference possible:

**NWDSA • Grow the Good
• Kaiser Permanente
Community Fund • Meyer
Memorial Trust**

Concordia University • Oregon
Council on Developmental Disabilities
• David Douglas School District

OHSU • Multnomah County
Developmental Disabilities Services •
Portland Public Schools • The Standard
• Clark County, Washington • Becker
Capital Management • Oregon Health
Authority Office of Equity and Inclusion
• Lifeworks • Multnomah Education
Services Division • Community Vision,
Inc. • Northwest Health Foundation •
United Cerebral Palsy of Oregon and SW
Washington • TASH



This year's conference kicked off with a new Friday Master Session.



*“Chase your dreams, never let them fade away
Live life to the fullest and never be afraid
To show who you really are”
Linnea Goranson, Self-Advocate*



*“We began to realize that we didn’t have to
try to figure it out on our own. Information,
support, and community were available. We just
had to grab the extended hand that was given
to us ... And eventually, we did. We have been
thankful ever since.”*

*Advocate and NWDSA volunteer (and Nickel’s
mom) Mindy Parker.*



Top Fundraising Teams:

| | |
|------------------------------|-------------------------|
| <i>Bullwinkles</i> | <i>Archer’s Team</i> |
| <i>Rootbeer Bandits</i> | <i>Team Percy</i> |
| <i>Soleyl’s Bright Shine</i> | <i>Team Birdcatcher</i> |

17th annual Buddy Walk® Festival

The sun shone brightly on the 2015 Portland Metro and SW Washington Buddy Walk® Festival this past September, which included familiar friends such as Newell Briggs, Tony Starlight, Central Catholic Cheerleaders, Cloud City Garrison, and Hooperville, as well as some new friends—pirates from PXYar, and Shelbi and Teresa performing as Elsa and Anna from *Frozen*.

Self-advocate Linnea Goranson made an inspiring speech about why inclusion has been important in her life and 14-year career as an office assistant at Portland State University Parent and volunteer Mindy Parker spoke to the crowd about what the support of the NWDSA community has meant to her daughter and her family.

Through donations, pledges, silent auction, and raffle ticket sales, over \$47,000 was raised by a few thousand self-advocates, supporters, family and friends. These funds will help fund important community programs across Portland Metro area and SW Washington for the coming year.

We would like to thank the following sponsors for making Buddy Walk 2015 possible:

| | |
|-------------------------------|------------------------------|
| Latitudes | The Children’s Clinic |
| Rose City Sound | Widmer Brothers |
| Parties Inc. | Summit Orthopaedics |
| Anchor Insurance | Regence |
| Campbell Global | Dreyer’s |
| Windermere Real Estate | Wolfer’s |

And event partners including: Moda Center, Key Tent Co., Sysco Portland Inc., JJ Jump, Kidz with Ice, and our Buddy Walk volunteers.



Entertainment for Buddy Walkers provided by Newell Briggs (left) and Tony Starlight (right).





Founded in 2004 by Sydney Shook and Jamie Burch with a mini-grant from the NWDSA, Open Arms is a parent-driven playgroup for children age birth through five with disabilities, and their families.



Ten years and going strong! 2015 Bike Week clinic empowered over 50 cyclists to bike on!

Open Arms returns to Portland, expanded to include cross-disability families

Open Arms Playgroups are fun places where children play and parents connect! These playgroups are for families with children aged birth through five. There are two playgroups, serving families in Portland and Vancouver.

Previously, the Portland Playgroup focused on children experiencing Down syndrome, but now the group is cross-disability which means that *all* families with children age birth through five with a disability are welcome! The Vancouver Playgroup is still for children with Down syndrome.

Portland Open Arms, birth - 5 with disabilities

Second Wednesday of each month, 10 AM thru Noon
Eastside Free Methodist Church
650 SE 139th Ave, Portland, OR

Vancouver Open Arms, birth - 5 with Down syndrome

First Sunday of each month, 3:30 thru 5:30 PM
Central Park Childcare
2115 East Mcloughlin Blvd, Vancouver, WA

NWDSA's Bike First cyclists take summer for a spin during Bike Week

It was a week of triumph and achievement for the 52 aspiring cyclists enrolled in NWDSA: Bike First! and Quick Start! / Refresher Clinics. For the tenth year running, NWDSA's Bike First! week-long clinic brought smiles to the faces of the riders, volunteers, parents and guardians alike. Cyclists of all ages and abilities made excellent progress developing the skills needed to ride typical two-wheeler bicycles.

The spirit of the community and inclusion rang loudly throughout the week as 45 outstanding volunteers contributed their time, energy, and compassion.

Thank you to Original Joes and Boomers BBQ for lunch each day (they've been with us for ten years!), Concordia University for donating the use of the gymnasium (eight years!), Multnomah Athletic Foundation (eight years!) and Safe Routes to Schools (seven years!).

If you'd like to read more NWDSA's Bike First! program, visit www.nwdsa.org/bikefirst

"Bike First! is more than a bike camp for [children with disabilities] – it's a family, a support network, a cheerleading squad and a one-stop miracle zone. Every participant takes his or her first solo pedal strokes to the sound of thundering applause, and every participant is honored in front of the group in a closing ceremony. It's a time to shine and grow and triumph." Heidi Swift, *The Oregonian*

Bike on!

College a reality

Continued from page 5

Kindergarten Readiness: NWDSA/ABI sponsored a workshop entitled “Getting Ready for the Big Day; Dive into Tools, Tips, Rights, and Partnerships for a Great Start to Kindergarten” featuring Chris Shank, Attorney DRO; Michael Bailey, DRN; Alicia Delashmutt, Parent Advocate; Esther Harris, PPS Parent Liaison; Jamie Burch, Clark County Parent Coalition; Dr. Ruth Falco, PSU; Mirsa Lopez, OrFirst; and Stephanie Hunter, OTAC. This is the first of hopefully many future trainings focusing on supporting families through Kindergarten transition.

Kindergarten Inclusion Cohort: This one-year program gives parents the knowledge and advocacy skills necessary to help their child with a significant developmental delay gain access to an inclusive kindergarten placement.

Children’s Agenda: NWDSA/ABI joined with over 60 advocacy groups and coalitions to identify key policy changes that will improve life for children in Oregon, including kids experiencing disabilities. Read the Children’s Agenda at www.orunitedforkids.org/childrens-agenda

NWDSA/ABI introduced two initiatives to the Children’s Agenda including creating and expanding inclusive college options for our youth with intellectual disabilities and creating tax-free savings accounts for individuals with intellectual disabilities.

Collaboration with Disability Rights Oregon: NWDSA/ABI Executive Director Angela Jarvis-Holland was recently appointed membership on the Disability Rights Oregon Board. NWDSA/ABI and DRO have built a valuable partnership over many years, working together on the issues of seclusion and restraint among others. Attorney Chris Shank from DRO has presented and collaborated on many projects with ABI to educate parents about legal solutions. Angela is enthusiastic about the opportunity to continue learning from this partnership.

There is a saying that goes, “Difficult roads lead to beautiful destinations.” Parents and families brought together by the common needs of our children know that this road is easier to travel with the support of the community, and change happens and progress is made when we unite to advocate for a better future for all children.

National Down Syndrome Awareness Month

Each year, the month of October is a chance to celebrate family, friends, and loved ones who experience Down syndrome, and share their abilities and accomplishments within our communities and nationwide.

You can find high-resolution, downloadable images depicting children and adults with Down syndrome in our community: www.nwdsa.org/events/national_down_syndrome_awareness_month.html



Parents traveled to Salem to advocate for the rights and funding that families need, and to share the message of how diversity strengthens communities. Oregon State Representative Lew Frederick (upper left) makes time to meet and talk with Jasmine and Nickel.



NWDSA staff meets with Portland Public School Superintendent Carole Smith, other parents, community members, and teachers to advocate for school funding.



Kindergarten Inclusion Cohort graduate leads 2015/2016 KIC session

The 2015/2016 Kindergarten Inclusion Cohort is underway with a new co-coordinator on board. Carrie Hutchinson is a parent and KIC graduate with a degree in Special Education from Concordia University. As KIC co-coordinator, she works alongside NWDSA/ABI staff, helping to facilitate in-depth, interactive, and best practices-driven trainings from educational and legal professionals.

This year's cohort will provide information about positive behavior supports, special education law, IEP goal-writing, UDL, person-centered thinking, and much more.



Disability Rights Oregon achieves legal victory

In January 2012, attorneys from DRO filed a class-action lawsuit against the state of Oregon, contending that its use of "sheltered workshops" violates the Americans with Disabilities Act by segregating people with disabilities from the workforce.

In September 2015, the parties reached a proposed settlement potentially allowing employees with disabilities in Oregon to find opportunities outside of segregated work environments.

Thanks to the ruling, more than 1,100 disabled Oregonians who currently labor in sheltered workshops, sometimes earning pennies an hour to do menial, repetitive tasks, will get a chance in the next seven years to take jobs in the general workforce that pay a living wage.

Commemorating 25 years of the ADA

This summer, the City of Portland's Office of Equity and Human Rights, Portland Commission on Disability, and community partners organized celebrations around the city to commemorate the 25th Anniversary of the landmark Americans with Disabilities Act, a civil rights law that prohibits discrimination based on disability and guides employers and businesses on accessibility and accommodation requirements.

Consider an end-of-the-year gift to NWDSA/ABI

NWDSA/ABI is a grassroots organization and every dollar is critical to our mission. We thank every person, foundation, or business who donated time, talent, or treasure to NWDSA/ABI in 2015, and we ask for your continued support in 2016.

Make a donation today at www.nwdsa.org/donate

- Ask your company if they have a matching program.
- Do your holiday shopping through Amazon Smile. Find the direct link at www.nwdsa.org/donate
- Join NWDSA Rewards for online shopping deals at www.nwdsarewards.com
- Link your Fred Meyer Rewards Card to NWDSA and your purchases will benefit our programs. Info at nwdsa.org/donate
- Donate your vehicle through www.donateforcharity.com
- Make an in-kind donation for our silent auctions or raffles
- Sponsor the All Born (In) Conference or Buddy Walk Festival
- Volunteer! Learn more by calling (503) 238-0522

INCLUSIVE EDUCATION is critical to our mission of creating an inclusive civil society.

EMPOWERED FAMILIES are equipped and supported to create inclusive communities where everyone belongs.

A HOPEFUL FUTURE is the greatest gift you can give, by supporting a community in which people of all abilities can contribute and thrive.



NWDSA/ABI at the 2015 TASH Conference

For 40 years, the TASH Conference has impacted the disability field by providing innovative information and resources, facilitating connections, and helping attendees reignite their passion for the full inclusion of people with disabilities in all aspects of community life.

The 2015 TASH Conference was held in Portland on December 2nd thru 4th. NWDSA/ABI staff and advocates presented several sessions and workshops. Executive Director Angela Jarvis-Holland was surprised with a special recognition award for all of her hard work and advocacy.



Fishing, games, and relaxing in the shade at NWDSA's 2015 Summer Social at Camp Angelos.





Images from the 2015 NWDSA/ABI wall calendar. Photos by Jared Holmgren (jaredholmgren.com), Jodi Collins (urban-photography.com), and Jaime Kae Hazen Photography & Design.



Celebration

Continued from page 1

By organizing parents, educating them in the benefits of early intervention, and training them to be their children's first therapists and researchers, PRIDE laid the groundwork for Early Intervention as we know it today.

When it came time for Eric to enter kindergarten at his local school, Edie launched herself into 13 years as an advocate with Portland Public Schools. As far as the Brown family knows, Eric was among the first students with Down syndrome to graduate from an Oregon high school with a regular diploma. This diploma didn't come easy, though, and Edie rolled up her sleeves and worked with teachers and administrators alike to help Eric and the schools be successful. Edie's children all remember her tireless advocacy and the many battles she fought over the years to pave the way for Eric's success. Her son Ken, who was a high schooler when Eric was born, remembers helping her with countless letters to the schools, finding the right balance between emotion and diplomacy that would yield the results that Eric needed. She struck that balance with grace, and was recognized by PPS with an engraved platter thanking her for her contributions to the district's special education department.

Eric moved out of his parents' home when he was 18 and moved into an apartment with his sister Christina, who had become a 1st grade teacher. Christina continued her love of teaching with Eric. This time together prepared Eric for independent living.

Today Eric lives in an apartment with an old friend he's known since his days at PRIDE. For the past 20 years he has worked in the facilities department at Mentor Graphics in Wilsonville, and is a valued and well-regarded employee. He goes to the gym with his brother Ken, he is known for his almost daily letters, and he does a spot-on impersonation of his mom, especially her slightly disgruntled, "Oh, Eric." Sadly, Edie Brown passed away this past May, and the weekend before she died she sat back and watched Eric work the room at a family gathering. She looked over at her son Ken and said, "It's working. All this work has come to something good."

Edie left a lasting legacy for all of us who carry on her fight for inclusion. She believed that all people deserve to be a part of our society, and she worked to make that belief a reality for her son, and so many others besides. She is a testament to the power of a parent who stands up to the status quo.

Editor's note: The family of Edith Brown (1933-2015) set up a memorial fund with NWDSA/ABI. Inspired by her commitment to inclusion, those funds will support the Kindergarten Inclusion Cohort. We are humbled by Edie's work and her family's desire to carry on her legacy in this way. To learn how to contribute to the fund, please visit nwdsa.org and click on the "donate" tab.



Kimberly Bailey-Tweed and Mindy Parker hosted a successful Toast to Inclusion fundraiser in December to benefit the Kindergarten Inclusion Cohort. This event has fast become a favorite holiday merry-making tradition for the NWDSA/ABI community. Thanks to the parents and volunteers who helped organize this fun event!

Become a Voter Ambassador

Want to make sure the voices of people with disabilities are heard in 2016? Become a Voter Ambassador in your community. Learn more about how you can help at <http://droregon.org/become-a-voter-ambassador/>

Events • Full calendar & details at www.nwdsa.org/events

JAN 16, 8:45 AM - 1 PM - Reciprocal Learning Community: Tools & Strategies that Support Positive Behaviors • **PLEASE NOTE LOCATION CHANGE:** Montavilla United Methodist Church • 232 SE 80th Ave, Portland • Register at www.nwdsa.org/events or (503) 238-0522

APR 23, 2016, 8:30 PM - 5:30 PM - All Born (in) Conference: 11th annual Cross-Disability Best Practices Inclusive Education Conference • Airport Holiday Inn, Portland • Learn more and pre-register at www.nwdsa.org/allbornin

Drop-In Hours, Thursdays, 12 - 2 PM: Explore resources, get answers to questions about IEPs, school, home, development, behavior & more • NWDSA Resourcefulness Center • 11611 NE Ainsworth Circle, Suite 321 • Portland, OR • **PLEASE NOTE: CLOSED DECEMBER 24th & 31st**

Open Arms Playgroups: Join other parents and their children age 0 - 5 to share, play, learn, and have fun!

Portland: Cross-disability • 2nd Wed of every month • 10:00 AM - Noon • **PLEASE NOTE LOCATION CHANGE:** Earl Boyles Elementary School • 10822 SE Bush St, Portland

Vancouver: Down syndrome • 1st Sun of every month • 3:30 - 5:30 PM • Central Park Childcare, 2115 East Mcloughlin Blvd, Vancouver WA

Club Upside Vancouver: Where parents can share and children of all ages and abilities can play • 2nd Saturday of every month • 2:00 - 4:00 PM • St. Andrew Lutheran Church, 5607 NE Gher Road, Vancouver WA

NWDSA

northwest down syndrome association

Angela Jarvis-Holland
Executive Director

NWDSA Board of Directors:

Steven Holland
Abigail Braithwaite
Angela Jarvis-Holland
Angela Frome
Becky Adelman
Guiseppa Lipari
Michelle Wallace
Ruth Falco
Isis Sanchez

For more info please visit
www.nwdsa.org
or www.allbornin.org

The NWDSA is organized for charitable, scientific & educational purposes to provide families and individuals with Down syndrome social opportunities, support, education and information.

The NWDSA is a registered non-profit corporation in Oregon and has 501(c)3 tax-exempt status with the federal government.

Down syndrome is a genetic condition that occurs in approximately one of every 691 live births. The chance of having a baby with Down syndrome is not affected by where you live, social class or race. Having a baby with Down syndrome does not mean you did anything wrong: nothing done before or during pregnancy causes Down syndrome. In recent years, our community has seen incredible success in school, community and employment that would have been hard to imagine a generation ago. High expectations, coupled with appropriate supports, allow our children to live full, rich lives as contributing community members.

NWDSA

northwest down syndrome association

P.O. Box 9127
Portland, OR 97207

Each board member of the NWDSA has firsthand experience with the joys and the hardships of caring for a child with individual needs. We understand the importance of connecting with other families and how much we rely on these relationships when we encounter the inevitable challenges. We also celebrate each others' victories, making the journey so much richer. The Board of Directors of the NWDSA consists of volunteers and is supported by enlightened professionals. For more information on our organization and ways in which you can become involved or make a donation, please visit our website at www.nwdsa.org or call (503) 238-0522.

Para comunicarse en español, llame a Sheyla Hirshon (503) 239-1509 o Isis Sanchez (503) 442-5817



Please Recycle



this newsletter

Stepping Up staff

Editor: Abby Braithwaite

Production & Design:

Joni DeRouchie

A PDF of this newsletter and all the past issues are available for download at www.nwdsa.org



facebook.com/nwdsa

Save the date!



11th Annual all born (in)

Regional Cross-Disability Best Practices
Inclusive Education Conference

"We are all born (in)" - Collaborating to support inclusion & equity

Portland Airport Holiday Inn • April 23, 2016