



# Stepping Up!

News from ABI & NWDSA  
Programs of NW Disability Support

Issue 27  
Summer 2019

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## Circle of support: Kindergarten Inclusion Cohort & the importance of relationships

By Jamie Burch

Moving from early childhood to school years can be a confusing and sometimes disempowering experience for parents of children with disability. We created the Kindergarten Inclusion Cohort (KIC) to provide parents with tools and guidance to help them navigate this transition and become strong advocates for their child's inclusive placement in the regular classroom. But the KIC also provides an additional vital resource—a community of other parents to lean into for support.

Anna Herbig graduated from KIC in 2017 when her daughter, Hattie, was heading into kindergarten. Anna shared, "[KIC] definitely kept us on track. My family learned about rights and the laws around IEPs." Anna also gained knowledge about informed decision making, behavior, communication supports, IEP goal writing, and how to successfully work with the school team while confidently holding strong to her personal values.

As Shakyra Rosario prepared for her daughter Soley's transition to Kindergarten, she looked to Anna for mentorship and support.

## Pedi Power

By Peyton Douglas-Doran

Getting a pedicure can be tricky for me.

Sometimes having my feet touched is a little uncomfortable. My mom says the technical term is *Sensory Defensiveness*.

The other day, I went to a pedicure party with my friend Adara. I was pumped up to get to the nail salon. The polishes were really fancy. I picked a bright red color.

See "Power " • P18

See "KIC" • P12



*RLC planning session with parents & professionals*



*RLC workshop: Hopes, Dreams & Possibilities, Nov 2018 (above)*

*Rosemary Nambooze of Angel's Center NGO in Uganda stopped by RLC during her visit to the U.S. (below)*



## Letter from the Board

Greetings to all our friends and families. We wish you all a fun and happy summer! It is hard to believe that we have been leading NWDSA—now under the banner of NW Disability Support—since 2002. So many incredible achievements have happened over this time; it is truly impossible to pick a highlight. Suffice it to say that the journey of our organization is reflected in the lives of our children, many of whom were very young and now are attending college, transition services, working, or carving out their own unique life experience. Above all they believe in themselves, and their families believe in them!

Our growth from an all-volunteer group to a professional staff supported by dedicated volunteers is a result of our trainings and advocacy work, and of course the All Born (in)Conference. We have made a difference in the lives of thousands of individuals and their families, and we have done this together.

Back in 2002, board members dedicated themselves to identifying the core values that would drive our work. We are proud to say those values guided us then, light the path today, and will continue to do so into the future. Although times change, and we as an organization have evolved and grown, our values never change—our belief in the potential and the right of each person with a disability to live a full and joyful life, included and respected in their community, and the right of each family to be empowered to help their children in the quest to reach these ideals.

I have been blessed and deeply honored to have served as President of the NW Disability Support/NWDSA/ABI since 2003. With this letter I am passing the baton to Michael Bailey who will be taking on the role as President effective July 1, 2019. Michael has served on the Board for various tenures since our involvement in 2002 and is the parent of a daughter with Down syndrome. Michael has been a committed and key professional resource to our organization since its inception and has a distinguished resume of professional service and involvement in the disability community locally and nationally.

I will remain serving you as the organization's Vice President and Treasurer. I look forward to the upcoming Buddy Fest NW on September 21st. I hope to see you all there!

Steven Holland  
NW Disability Support



## World Down Syndrome Day Celebration

It's our annual tradition to gather on March 21st to honor and celebrate friends, neighbors, coworkers, and loved ones experiencing Down syndrome. This year, we once again filled the beautiful Lagunitas Community Room to enjoy pizza, music, and entertainment. Thanks to Lagunitas for providing beer, Avi Haviv for beautiful music, Emmy Blue and Squatchie, and all of the community volunteers who helped make it happen!



## Summer Social

Our traditional summer get-together for families within the Down syndrome community. Camp Angelos is a beautiful, fully-accessible retreat nestled in the Sandy River Valley. Activities include bounce houses, music from Avi Haviv, shaded areas and cool river water, games, food provided by Holy Trinity Greek Orthodox board (organizers of the Portland Greek Festival), and so much more. This event is free; RSVP is required. Don't miss it!

**SUMMER SOCIAL 2019**  
**SUN AUG 11 • NOON–3 PM**

Camp Angelos  
 32149 SE Stevens Rd  
 Corbett, OR

RSVP Required:  
[abicommunity.org/events](http://abicommunity.org/events)

## CALENDARIO DE EVENTOS

### Grupos brazos abiertos

**Portland** • 2do martes de cada mes • 10:30 AM–12:30 PM

**Vancouver** • 1er sábado de cada mes • 2:30–4:30 PM

**Salem, Silverton y las áreas asus alrededores** • 3er martes de cada mes • 10 AM–12 PM

**Hillsboro** • Día y hora por ser determinado

**Si está interesado/a en ser un coordinador voluntarios de los grupos brazos abiertos en su área, por favor contáctenos (503) 238-0522**

### Horas abiertas para apoyo con la educación especial

Todos los jueves, sept–junio

### Reunión en español para padres

2° y 4° miércoles de cada mes, sept–junio

### Social de verano

Domingo, 11 de agosto

### Campamento juvenil de justicia social

Agosto 15–18

### Cohorte de inclusión de kindergarten

Septiembre 2019–mayo 2020

### Festival de amigos del noroeste

Sábado, 21 de septiembre

### Conferencia Todos Nacidos (dentro)

17 y 18 de abril de 2020

**Para más información, lláme a Maria al (503) 262-4029**

**HEMOS AMPLIADO NUESTRA BIBLIOTECA DE RECURSOS EN LÍNEA EN ESPAÑOL.**  
[abicommunity.org/espanol](http://abicommunity.org/espanol)

## Mirando al futuro: ¿Qué viene después de la secundaria?

Por Elvira Sanchez

Tengo tres hijos: Paola, de 22 años, Natanael, de 18 años, y Uriel, de 15 años.

Natanael fue diagnosticado con ADHD y ADD en el kinder y su distrito escolar lo colocó en un Plan de Educación Individual (IEP).

Pasaron diecisiete años y mi hijo estaba a punto de terminar la escuela secundaria. Comencé a preguntarme: “¿Qué habrá para mi hijo después de la secundaria?”

La escuela comenzó a hablar sobre un plan de transición que tenían para mi hijo. Francamente, estaba confundida con todo el tema de la transición.

Tuve el placer de conocer a Angela Jarvis-Holland de ABI y ella me informó sobre los servicios y recursos disponibles. Me puso en contacto con María, la Coordinadora Bilingüe de ABI, y comencé a aprender acerca de la transición de la escuela secundaria. Aprendí que hay más de una opción disponible para mi familia.



Como padres, no estamos solos. Aprendí que no tengo que ser una experta en todas las materias, pero es importante conectarse con organizaciones como ABI para que nos ayuden y guíen.

También aprendí que a veces tenemos que abrirle el camino a nuestros hijos y no esperar a que otros lo hagan.

Este proceso me inspiró a no solo seguir aprendiendo, sino también a informar a nuestros jóvenes sobre sus opciones después de la escuela secundaria. Comencé un grupo de jóvenes con el propósito de ayudarlos a explorar sus intereses profesionales y a que se preparen para la vida después de la secundaria.

**READ THIS STORY IN ENGLISH ON PG. 19**

## Un año de crecimiento

por Maria Rangel

NWDSA/ABI continúa siguiendo nuestro plan de trabajo titulado “Rompiendo barreras para la inclusión” con el objetivo de aumentar el acceso a las familias que hablan español. Esto nos permite ofrecer los mismos servicios de alta calidad para todos, así como también respetar el punto de comienzo de todos y aumentar la cantidad de padres que hablan español que acceden al apoyo y los recursos a través de nuestra organización.

Uno de nuestros mayores logros este año fue poder ofrecer nuestro taller de entrenamiento de transición de kínder y más! en español por primera vez.

Colaboramos con Susana Ramírez de Disability Rights Oregon y Paulina Larenas de FACT Oregon para que esto fuera un éxito. Todos los recursos y materiales estaban disponibles en español y las sesiones de entrenamiento reflejaban el entrenamiento en inglés.

Fue muy importante poder ofrecer este taller en español y romper la barrera del idioma.

Pude ver un aumento de nivel de atención, participación, nivel de comodidad y de aprendizaje de los padres en comparación con sus experiencias en talleres en inglés con intérpretes.

Los comentarios de los padres confirman la importancia de presentar talleres en español. Una de las preuntas de la evaluación del entrenamiento fue: ¿Qué fue lo que más te gustó del entrenamiento?

Y casi todas la evaluaciones tenían como respuesta: “Todo estaba en español”

Como Coordinador Bilingüe, estoy agradecida de que ABI/NWDSA aprecie mi aporte en programas y entrenamientos, y que mi trabajo esté respaldado por los valores fundamentales de la organización.



*Enero de 2019—Susana Ramírez de Disability Rights Oregon presentando a padres en la sesión en español de Transición de Kínder y más*

*January 2019—Susana Ramírez from Disability Rights Oregon presenting to parents at the Kindergarten Transition Bootcamp Spanish track*

**READ THIS STORY IN ENGLISH ON PG. 12**



*Mayo de 2018—Trabajando con padres y profesionales de PPS para ayudar a romper las barreras para los padres que hablan español cuyos hijos reciben servicios de educación especial.*

*May, 2018—Working with parents and professionals from PPS to help break barriers for Spanish-speaking parents whose children receive special education services.*

## Message of gratitude

The 20th annual Buddy Fest NW festival and walk was a magical day of disability pride and celebration. The weather played a symbolic role by showering us with both rain and sunshine—much like our lives with Down syndrome. Perspective and perseverance were found in the joy, strength, love, and support of our community.

### Special thanks to everyone who helped make the day special:

Speakers Yoisy Sarao, Kirstin Kunihusa, Dan Jarvis-Holland, Emma Frome, Cody Sullivan, Matt Schweitz, and James Phillips for challenging all to presume competence, be coachable, and free our people!

Emcee Tony Starlight for contributing his talents for eight years in a row. Brian “The Unipiper” Kidd for leading our walk in weird Portland style. Wallace for kicking off the day with soulful sounds, and The Nu Wavers for bringing the dance party. Jonas Hartley for his unicorns, Looney Ballooney for his colorful art, and Central Catholic Cheerleaders for cheering us on.

Rose City Sound for amplifying our message, Key Tent Services for keeping us dry, FickleZeal Photography for capturing the day, Parties, Inc. for bouncy fun, Kidz with Ice and Franz for goodies and treats.

Thank you to our volunteers who made it all possible!

Alongside our sponsors, planning committee, staff and board, and continued vision to create a loving and inclusive society of all people experiencing disability including Down syndrome, we created another memorable celebration and fundraiser for NWDSA.



**REGISTER FOR BUDDY FEST NW 2019**  
 Sept. 21st • [buddyfestnw.org](http://buddyfestnw.org)  
 See the insert for more info

## Thanks to the sponsors & in-kind donors who made this event possible!

Oregon ABLE Savings Plan • Campbell Global • Cool Events • Rose City Sound • FickleZeal Photography • Key Event Services • Odd Fellows • Aris Construction Services LLC • Parties, Inc • ABI: Bike First! • Lithtex Printing Solutions • Danner • Go To Ortho • Infinity Impressions • Sysco • Parker, Smith & Feek • Pumper Car • Widmer Brothers Brewing • Kidz with Ice • Dreyer's • Chubb Group of Insurance • Tony Starlight • The Unipiper • Wallace • The Nu Wavers • Breakside Brewing • Moreland Neighborhood Dental • Raw Materials in Motion • Mott's Carpet Cleaning • Bandon Dunes • On Point Community Credit Union • Central Catholic Cheerleaders • Portland Fire Department & Portland Police • All the volunteers!



Top fundraising teams: Bullwinkles (pictured below), Dan's Vikings, Soley's Bright Shine, Archer's Team, Team Olav

Top fundraising individuals: Eric Cerdena, Shannon Larissey, JD Scobba, Donovan Smith, Lorraine Daily



## "Support Inclusion; Reject Segregation. We All Belong!"

All Born (in) Cross-Disability Best Practices Educational Inclusion Conference—  
Saturday, April 6, 2019.

The 14th annual All Born (in) conference brought together a diverse audience of parents and caregivers, individuals with disabilities, youths, educators, professionals, and allies from Oregon, Washington, Idaho, California and beyond, to join the movement toward a more inclusive civil society.

Saturday was jam-packed with 35 sessions including sessions presented entirely in Spanish, and a youth track focused on amplifying the youth voice for power.

Guadalupe Guerrero, Superintendent of Portland Public Schools, noted the power of working together to embrace and support inclusion in our community.

LeDerick Horne, disability advocate and poet, set the tone for the day with his keynote about promoting disability pride and the importance of self-advocacy, telling your own story, and finding strengths within. He shared strategies for removing stigma by using disability as a positive

identifier instead of hiding it. His spoken-word performance of "Dare to Dream" left everyone feeling inspired.

Sessions covered topics such as co-teaching, high expectations, kindergarten inclusion, IEP, positive behavioral supports, radical self-care basics, disability history, LEAP Model, UDL, post-secondary education, employment, Oregon ABLE Savings Plan, and much more.

Local and national presenters included Dr. Ritu Chopra (Executive Director, Paraprofessional Resource and Research Center), Sharon Lewis (Disability Policy Expert), Stephanie Smith Lee (senior policy advisor), Heather Lindsey (Oregon Department of Education), and others.

The closing presentation by participants from the youth track included commitments to social and environmental justice, as well as "I am" poems.

The day ended with music, cake, and community celebration.

### SAVE THE DATE!

15th Annual All Born (in) Conference  
April 17 & 18, 2020  
Portland Airport Holiday Inn



*"AMAZING! As a direct support provider, I am taking away so much that is helpful to my work."*

*"...it is the only time I feel like part of the disability rights community, not just a solo special ed teacher."*

*"My son's talents and needs may look a little different than most, but he deserves no less out of his life than anybody else: relationships, deep friendships, goals, opportunity, connection, and value."*



## 2019 CONFERENCE PREMIER SPONSOR: Portland Public Schools

West Linn-Wilsonville School District • Kuni Foundation • Oregon ABLE Savings Plan  
 • Independence NW • Multnomah Early Childhood Program • Columbia Regional  
 Program • Concordia University • Highline College • ACHIEVE • Clackamas Education  
 Service District • Early Learning Multnomah • Multnomah County • Oregon Council  
 of Developmental Disabilities • Oregon Department of Education • Clark County,  
 Washington • Multnomah Education Service District

We greatly appreciate the generous contributions of speakers, presenters, collaborators, donors,  
 and volunteers • Special thanks to the Universal Design for Living and Learning Coalition



### “College & Career Success for All”

ABI’s Think Inclusive College (West Coast Coalition) Adult Transition Summit—Friday, April 5, 2019.

Nearly 140 parents, young adults, and professionals came together for a full day of information, networking, and advocacy. Guided by the impacted disability community and rooted in the values of the Developmental Disabilities Bill of Rights, ABI works to open more doors to inclusive college options for students with intellectual disability.

NW Disability Support’s Jamie Burch and Angela Jarvis-Holland shared the program’s work and accomplishments, including Oregon’s first four-year program at Portland State University and ABI’s Social Justice Youth Program—an inclusive youth leadership initiative for young adults age

16-25 with and without disability.

Candace Pelt, with the Oregon Department of Education, presented a keynote speech about inclusive education for all, after which participants split to follow their respective tracks; “Why Not Me?” offered five workshops for the youths, and “Real Lives & Communities” offered 10 workshop choices for parents and professionals.

The afternoon closed with a keynote by the youths who shared their dreams that included inclusive college, employment, and living a full, meaningful life based on their interests, passions, and goals.

The national and local speakers who devoted their time to this event deserve many thanks, as well as our sponsors Highline College and Multnomah County. And thank you to the youths for leading the way!

## OPEN ARMS MONTHLY PLAY GROUPS

For children 5 & under with disabilities and their families to meet, play, and share.

## OPEN ARMS SUMMER SCHEDULES VARY

Visit [abicommunity.org/events](http://abicommunity.org/events) for updates

### PORTLAND

2nd Tuesday of the month  
10:30 AM–12:30 PM

Earl Boyles Elem School  
10822 SE Bush St • Portland, OR  
Contact: Maria (503) 238-0522 • habla Español

### VANCOUVER

1st Saturday of the month  
2:30–4:30 PM

Unitarian Universalist Church  
4505 E 18th St., Vancouver, WA  
Contact: Kirstin (541) 294-3873  
Mayra (509) 310-9905 • habla Español

### SALEM, SILVERTON & SURROUNDING AREAS

3rd Tuesday of the month  
10:00 AM–12:00 PM

Silver Falls Library  
410 S Water St, Silverton, OR  
Contact: Kara (503) 871-3636

### HILLSBORO

Day & Time TBD

**If you are interested in being a volunteer Open Arms Coordinator in your area, please contact (503) 238-0522**

## SPECIAL EDUCATION SUPPORT DROP-IN SEPT THRU JUNE, NOON–2 PM EVERY THURSDAY

*Special Education is complicated; you don't have to go through it alone.*

Resources, support and advice around inclusion, IEP goals, transition, meeting prep, etc. Spanish support available: Maria (503) 262-4029.

Every Thursday during the school year; by appointment during the summer—call (503) 238-0522

Resourcefulness Center • 11611 NE Ainsworth Cir, Suite 321 • Portland, OR

## REUNIÓN EN ESPAÑOL PARA PADRES, SEPT A JUNIO 2° Y 4° MIÉRCOLES DE CADA MES, 10 AM–12 PM

Para padres que hablan español y tienen hijos con discapacidades. Conozca a otros padres, conectarse a nuestros programas y recursos.

Para más información, preguntas o detalles lláme al (503) 262-4029.

Centro de Recursos • 11611 NE Ainsworth Cir, Suite 321, Portland, OR

## SPANISH MEETING FOR PARENTS, SEPT THRU JUNE 2ND AND 4TH WEDNESDAY OF EACH MONTH, 10 AM–12 PM

For parents who speak Spanish and have children with disabilities. Meet other parents, connect to programs and resources

Resourcefulness Center • 11611 NE Ainsworth Cir, Suite 321, Portland, OR

**RSVP & registration links at [abicommunity.org/events](http://abicommunity.org/events)**

## ABI CROSS-DISABILITY EVENTS

### SOCIAL JUSTICE YOUTH CAMP / SUMMIT • AUG 15–18

For youths age 16–24 with and without disability • Application required • Learn more: [abicommunity.org/youthcamp](http://abicommunity.org/youthcamp)

### KINDERGARTEN INCLUSION COHORT • SEPT 2019–MAY 2020

Nine-month-long program of interactive and best practices-driven trainings for parents whose child will be starting kindergarten in September, 2020 • Application required • Learn more: [abicommunity.org/kic](http://abicommunity.org/kic)

### ALL BORN (IN) ANNUAL CONFERENCE • APR 17 & 18, 2020

## NORTHWEST DOWN SYNDROME ASSOC EVENTS

### SUMMER SOCIAL • AUG 11 • 12:30 - 3:30 PM

Annual get-together at Camp Angelos in Corbett, OR • RSVP required

### BUDDY FEST NW • SEPT 21 • 10 AM–1:30 PM

See insert for more info

## Co-taught Head Start inclusive classrooms

In 2016, Clackamas ESD's Head Start to Success and Early Childhood Special Education (ECSE) programs created a collaboration with Canby School District. The project pairs special education teachers and classroom assistants with Head Start teaching staff in a co-teach model. The staff work side-by-side in the classroom engaging and teaching all enrolled children. Teachers work together on lesson plans, ensuring that all children are offered rigorous instruction in developmentally-appropriate content and that any child with a disability is supported in fully participating in the activities with their peers.

The data on children's progress has been impressive. In the first year, children on ISFPs improved their scores an average of 13 percentage points more than children on IFSPs in non-co-taught classes. Children enrolled in the co-taught classroom who were not on an IFSP improved their scores an average of four percentage points more than children without IFSPs in other classrooms. This year, at the mid-year assessment, on average, the children on IFSPs in the co-taught classrooms started the year with fewer skills than their peers in non-co-taught classrooms, yet at the winter checkpoint they had surpassed their non-co-taught peers in all but social emotional skills. Their progress on social skills was still impressive, given the fact that many of the children on IFSPs started well below expected levels for their age and progressed significantly.

Nancy Barber, Head Start teacher in the co-taught classroom says, "The benefits are endless. Co-teaching gives children a rich, diverse, and strong community to thrive in. Two heads are always better than one. It is a positive and successful strategy to have in any classroom."

Leslie Arbuckle, Head Start director, explains that, "Co-teaching facilitates collaboration among staff so that all children are supported. Everyone comes to the table with different experiences and philosophies and beliefs but together we are working for the good of all kids in the classroom. Through collaboration, all team members are growing in their knowledge and skill."

Clackamas ESD ESCE program intends to extend the co-teach model to other school districts in collaboration with Head Start to Success for the 2019-20 school year.

Families of children in the program are happy with their experiences. One mother said, "Co-teaching helped give [my child] better social skills, and self-esteem. It gave her a chance to interact and form friendships. We are very thankful for her to have the opportunity to experience co-teaching from Head Start."

When we partner together, all children benefit!



*A collaborative project by early childhood educators in Clackamas County is proving that all children in inclusive classrooms can benefit academically and socially given the right support.*

## A year of growth

By Maria Rangel

NWDSA/ABI continues to follow our work plan entitled "Breaking Barriers to Inclusion" with the goal of increasing accessibility to Spanish-speaking families. This allows us to offer the same high-quality services to everyone as well as honor everyone's starting point and increase the number of Spanish-speaking parents accessing support and resources through our organization.

One of our biggest accomplishments this year was offering our Kindergarten Transition Bootcamp in Spanish for the first time.

We collaborated with Susana Ramírez from Disability Rights Oregon and Paulina Larenas from FACT Oregon to make this a success. All resources and materials were available in Spanish and the training session mirrored the English-language training.

It was important to be able to offer this bootcamp in Spanish and break the language barrier. I could see an increase of engagement, participation, comfort level, and learning with parents, compared to their experiences in English-language-only workshops with interpreters.

Parent feedback confirms the importance of presenting workshops in Spanish. One of the questions in the training evaluation was: "What did you like most about the training?" Almost all the evaluations had the answer: "that everything was in Spanish".

As Bilingual Coordinator, I am grateful that ABI/NWDSA appreciates my input on programs and trainings, and that my work is supported by the core values of the organization.

## "Cover Story" Cont...

Anna said, "I know my daughter going through the process ahead of [Soleyl] has been super helpful to Shakyra. Having support of others that have gone through it is priceless."

Shakyra replied, "I know that I can count on Anna unconditionally. She helped me be 100% prepared for the IEP meeting and came to support me during the meeting as well. She's without a doubt one of my best friends!"

For Shakyra, the best part of Soleyl's first IEP meeting was that "their main goal was inclusion like us. Inclusion means everything! We all belong and this needs to be normalized in schools. We all contribute to society."

For Anna, inclusion means, "that my daughter enrolls in general education, with the proper accommodations being honored, and learns alongside her same-age peers [without disabilities], and is being invited to birthday parties and playdates. The school secretary knows her teacher, not her IEP case manager."

Having high expectations and sharing your child's strengths at IEP meetings can help balance out the deficit-based process. Anna offered, "Don't go to meetings alone! Keep contact with all the team members. Attend the Kindergarten Transition Bootcamp through ABI/NWDSA. Read the state common core guidelines to come up with appropriate grade level goals."

Shakyra suggested, "Make sure to get a draft of IEP ahead of time to review. Come prepared and with an open mind. Bring someone to the meeting that has experience and can help if needed. Also have no doubt that you know your child best."

KIC offers a unique opportunity to create a circle of support with other parents and professionals. There is power in relationships, leaning into others, and having a network of peers and mentors.

Visit [abicommunity.org/news](http://abicommunity.org/news) to read more of Anna & Shakyra's journey.



*Shakyrá allows Soley's strengths to lead the way to kindergarten and beyond*

### KiC Reflections

"The program had a clear objective: to prepare the entire family for the processes and emotions involved with transition to Kindergarten." —Parent

"No information or webinars can replace relationships and support that are ongoing." —Parent

"KiC a good reminder to me why I am doing this for my son" —Parent

"The participants were well informed and enlightened about special education law and the system thanks to this natural community support." —MECP Supervisor

"I found [the family's] involvement to add welcome expertise about their daughter, which helped in the process." —Teacher



### Apply now for KiC 2019/2020

A nine-month-long program of interactive and best practices-driven trainings designed for parents whose child with Intellectual Disability will start kindergarten in Sept. 2020.

Prepare your family for the transition to kindergarten, learn to advocate for inclusive kindergarten placements for your child, and join a supportive community of parents, professionals, peers, and mentors.

You'll receive in-depth information and resources from educational and legal professionals in: Positive Behavior Supports, Special Education law, IEP goals to drive inclusive placement, and *so much more*.

**Apply at [abicomunity.org/kic](http://abicomunity.org/kic)**



*KiC graduates raise a glass to an inclusive future for their children*



*Attorney Chris Shank presents at the IDEA/IEP Ins-and-Outs workshop, Nov 2018*



*Joan Medlen presents at the Dual Diagnosis workshop, Feb 2019*



*Shanya Luther presents at How to Talk About Sex & Sexuality with Someone Who Experiences I/DD Workshop, May 2019*

## Here's to the dads

by Abby Braithwaite

With Father's Day just a few weeks in the rear-view mirror, we wanted to take a second to recognize Steven Holland, a dad who has been central to the workings of NW Disability Support since 2002.

Steven has volunteered countless hours managing financial statements, helping with grants, and participating in events, trainings, and conferences. While he has moved on from his role as president, he will remain an active board member, and continue to represent our work in the business community, introducing key sponsors to the heart of our work to build a more inclusive world.

As Daniel and Quinn's dad, Steven works hard to keep our children at the center of the organization, and to reach out to new dads and welcome them to this journey.

Thank you, Steven, for your years of dedication to this group, and to the dignity and inclusion of *all* children.

We are so grateful to all the dads who show up every day for their kids—on the playground, at IEP meetings, and in the home.



*Just a few of the dads who contribute to our organization and the community—(clockwise from top left) Felix & Violeta Eusebio, Daniel & Steven Holland, Kristian & Karley Burch, Randy & Whitney Anderson, Michael & Eleanor Bailey, and Adara, Corwin & David Morgan*



### *This New Piece of My Heart*

We are pleased to offer our New Parent Guide to new parents of babies with Down syndrome. Our goal is to provide useful, strength-based information and share positive stories about the joys, challenges, and experiences of raising a child with Down syndrome to help families just starting out on their journeys. If you are a new or expectant parent, please fill out the online request form at [nwdsa.org](http://nwdsa.org) to receive a copy.

*"The piece that stuck out to me the most was the letter from the doctor, and his experience of having a grandchild with Down syndrome and how that changed the way he shared the news with new families. I also remember thinking the resource guide at the end was helpful because it centralized all of the contact information for services we might need in the future."* — Camille

*"It was the only resource I read/received that congratulated me on the birth of our daughter. It had beautiful color pictures of children and families and messages of hope. Other resources were medical model-based and out-of-date. Thank you for providing a guide that helped us see future possibilities."* — Jamie

### *Este nueva pedazo de mi corazón*

Estamos muy contentos de poder proveer La Guía para Padres Nuevos de Niños con Síndrome de Down a los nuevos padres, así como a amigos, familiares y profesionales médicos. Nuestro objetivo es proporcionar información útil sobre el síndrome de Down y compartir las alegrías, los desafíos y las experiencias de criar a un niño/a con síndrome de Down.

Si usted es un padre nuevo o expectante de un bebé con síndrome de Down, visite [nwdsa.org](http://nwdsa.org) para solicitar una Guía para Padres Nuevos. Para más información, preguntas o detalles lláme Maria al (503) 262-4029.

*Jamie Burch's daughter required heart surgery before she was four months old. It was a scary time, and Jamie often wished she had other parents to talk to who had faced the same challenges.*

*In the years since her daughter's successful surgery, Jamie met other parents whose little ones were facing heart surgery and, like her, sought connection with others who'd been through it. Jamie had the idea to create a booklet that could be shared with families and professionals.*

*With NWDSA's support, Jamie compiled stories from 15 families about heart surgery.*

*Since its publication five years ago, Healing Hearts: Families' Experiences with Down Syndrome and Heart Surgery has provided hope, light, and support to many families.*

*Available at no charge at [nwdsa.org](http://nwdsa.org).*



*Angela Frome and Jace are a registered therapy team through Pet Partners. Jace, a sweet, gentle giant, provides comfort and companionship every Thursday during Special Education Drop-in at NWDSA/ABI Resourcefulness Center.*



*Artist Jessica Boyer and her commissioned portrait of Jace*

*Follow Jace on Instagram @jacethemastiff*

## Coming full circle at OHSU

Twenty years ago, Dan Jarvis-Holland, who experiences Down syndrome, was born at OHSU. His birth was not treated as a celebration by some of the medical staff and the family was not given resources that were encouraging or congratulatory. The information provided to his family about their new baby was negative and predicted struggles and challenges.

Dan's family, along with many other parents and professionals through NWDSA/ABI, has spent the last two decades working to provide strength-based resources to hospitals and medical professionals, and expand knowledge in the medical community about the positive realities of life with Down syndrome and other disabilities.

Last August, Dan spoke as part of a panel to second-year medical students. Dan—presenting as an expert on his own disability—spoke about real life and community and proved that every dour prognosis given to his family 20 years ago was misguided.

Two decades years after his family had been told by OHSU doctors that he would struggle to learn, read, or speak, Dan stood in front of OHSU medical students and taught them about the power of high expectations.

The presentation was very well-received by the students in attendance. One reached out to Dan via email and told him that their thinking about disability was changed in a real and indelible way.

Because of this work, parents of a new baby born with Down syndrome or other disability might receive hearty congratulations and positive, strength-based materials from medical staff, instead of grim conjecture and a list of thier child's possible deficits.



*Dan presenting his PowerPoint to OHSU medical students*



## Social Justice Youth Program Update

In the years since the inception of the Social Justice Youth Program in 2013, its members have grown into leadership and mentorship roles within the community as they find and use their voices for positive social change. The focus of the past year has been exploring who they are *beyond* their disabilities—figuring out what they want their futures to look like, what they have to contribute, what they want from their relationships, communities, jobs, school, etc., and how to advocate for themselves.

The group has contributed to transition programs, resource fairs, focus groups, workshops, and other community events. They've explored art museums, attended rallies and protests, presented at conferences, and worked with local artists and leaders.

This spring, the Transition Summit (April 5th) and annual All Born (in) Conference (April 6th) both featured Youth Tracks focusing on self-determination and empowerment. Sessions explored topics ranging from self-expression and body movement, supported decision-making, "raise your voice" poetry-writing, self care, and strength-based community building. The group prepared and delivered a presentation to over 500 parents, educators, and professionals at the conclusion of the conference.

Learn how you can participate in or donate to the Social Justice Youth Program at [abicommunity.org/youthcamp](http://abicommunity.org/youthcamp)



*Youth Program members participated in city clean-up efforts during Martin Luther King Jr. Day of Service (above)*

[f /socialjusticeyouthPDX](https://www.facebook.com/socialjusticeyouthPDX)    [✉ socialjusticeyouthpdx@gmail.com](mailto:socialjusticeyouthpdx@gmail.com)

***Social Justice Youth Program is currently accepting applications for the 2019 Summer Camp/Summit***

*A 3-day inclusive experience for youth ages 16-24—with and without disabilities—who are passionate about social justice issues and creative expression. Stay on campus and attend workshops and projects led by local activists, community leaders, and artists.*

***Learn more and apply: [abicommunity.org/youthcamp](http://abicommunity.org/youthcamp)***



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To join our mailing list and download PDFs of past issues, visit [abicommunity.org](http://abicommunity.org)

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Opinions published in *Stepping Up* are not necessarily those of NW Disability Support.



## "Power" Cont.

There were a lot of black chairs, but they were not just ordinary chairs; they were massage chairs! I sat down in the middle between Adara and my mommy. I really liked the feeling of the massage on my back and my neck.

I thought the water was way too hot, so my mom asked them to add cold water. She had to ask them a lot of times. When it finally cooled off, it felt good. Then it was time for the pedicure.

Jane sat down and got ready for the pedicure. It seemed like she wanted to get it over with. She tried to put my feet up on the white stool, but I wanted to keep my feet in the water for a little while. She did it again, and I put my feet back in the water again.

She did it again a third time, but I put them back in the water again. Jane looked at my mom and said, "She needs to put her feet up and let me do the pedicure, but she won't let me." My mom told her I need extra time to adjust to new sensations, especially on my feet. She asked Jane to give me a minute. But she seemed impatient. "Why not just forget about the pedicure and sit and enjoy the water," Jane said, and stormed off.

I will admit that I was a little depressed at the moment and I had a few tears. I wanted to just go home, but another part of me wanted to have the pedicure. My mom tried to comfort me by wiping away the tears and holding my hand. Adara held my other hand like a good friend.

But I still felt indignant. I said, "I'm ready for my pedicure now." My mom said she thought we might need to do it at home because everyone else was nearly done. But I said again, "I'm ready for my pedicure now." The manager asked if I just wanted to get the polish put on my feet. And I said, "Yeah, I would like that."

He asked Mary to help me. She was a kind and sweet person. She asked, "May I have your feet?" She took her time. When she massaged my feet and legs, the lotion felt good.

My mom and Abby (Adara's mom) were proud that I spoke up. They didn't mind that it took me a little while to get used to things, and they were excited for me to get my pedicure.

I thought my toes looked really cool. I did it!

Anyone can be anything. If you feel sad or happy or mad, listen to your heart. When you're worried about something, use your voice and your facial expressions to speak up and face your fears. You can overcome your fears and do it!

## Looking ahead: What comes after high school?

By Elvira Sanchez

I have three children—Paola, 22-years-old, Nathanael, 18-years-old, and Uriel, 15-years-old.

Nathanael was diagnosed with ADHD and ADD in kindergarten and his school district placed him on an Individual Education Plan (IEP).

Seventeen years passed and my son was about to finish high school. I began to ask myself, “What will there be for my son after high school?”

The school started talking about a transition plan they had for my son. Frankly, I was confused with the whole transition topic.

I had the pleasure of meeting Angela Jarvis-Holland from ABI and she informed me about the services and resources available. I contacted Maria—ABI’s Bilingual Coordinator—and I began to learn about high school transition. I learned that there is more than one option available to my family.

As parents, we are not alone. I learned that I do not have to be an expert in all subjects, but it is important to connect with organizations like ABI to help support and guide us.

I’ve also learned that sometimes we have to open the way for our children and not wait for others to do it.

This process inspired me to not only keep learning but also help inform our youth of their options after high school. I started a youth group with the purpose of helping them explore their career interests and getting ready for life after high school.

**FIND TRANSITION RESOURCES AT  
ABICOMMUNITY.ORG**

NWDSA and ABI are programs of NW Disability Support

### Board of Directors

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NW Disability Support is a registered non-profit corporation in Oregon and has 501(c)3 tax-exempt status with the federal government, organized for charitable, scientific, and educational purposes to provide social opportunities, education, support and information to families and individuals with disability.

The Board of Directors consists of volunteers and is supported by enlightened professionals. Each board member has firsthand experience with caring for a child with individual needs and understands the importance of connecting with other families.

**Our Mission:** Create and nurture a loving and inclusive community celebrating every person with a disability. We will accomplish this mission by empowering and supporting families and individuals who have been touched by disability. We will work to increase education, promote public understanding and acceptance, and toward full inclusion of individuals with disability in our community.

**ABICOMMUNITY.ORG—Cross-disability programs**

**NWDSA.ORG—Down syndrome programs**

**BUDDYFESTNW.ORG—Festival website**

**NWDISABILITYSUPPORT.ORG—Parent organization**

**ALLBORNIN.ORG—ABI Conference website**

**NWDSA**

northwest down syndrome association

**(abi)**

community

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Articulos en Español dentro del boletin!

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(503) 238-0522 • allbornin.org • nwdsa.org  
Para comunicarse en español,  
llame a Maria Rangel (503) 262-4029

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**EVENT BROCHURE ENCLOSED!**  
Register online at [buddyfestnw.org](http://buddyfestnw.org) or use the enclosed form to register by mail



**Upcoming events at a glance • more inside**  
Aug 15-18 • Social Justice Youth Camp/Summit  
Aug 11 • Summer Social  
Sept 2019-May 2020 • Kindergarten Inclusion Cohort  
Sept 21 • Buddy Fest NW  
Apr 17 & 18, 2020 • All Born (in) Cross-Disability Best Practices Educational Inclusion Conference  
[Full calendar at abicomcommunity.org/events](http://Full calendar at abicomcommunity.org/events)