



# Stepping Up!

Issue 26  
Summer  
2018

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News from ABI &  
Northwest Down Syndrome Association



*Emma & Dan, 2003*

## Sharing a dream of college

By Angela Jarvis-Holland and Angela Frome

Emma Frome and Dan Jarvis-Holland attended their first advocacy rally with us as small children 18 years ago in Salem as we protested cuts to Early Intervention.

As our children have grown up together, we’ve worked with many others to create a powerful social change organization and to raise our children to be kind and inclusive human beings.

Dan enjoys computers and experiences Down Syndrome, and Emma loves the outdoors and is a non-traditional learner. Over the years both have developed a strong sense of justice and have become powerful advocates. They’ve volunteered, attended, and presented at numerous rallies, events, and conferences together.

Five years ago, we asked our communities, families, and older youth what they wanted for their future, encouraging them to envision no limits on their dreams. A shared dream was thinking about college. Emma had choices and options; there was no college option for Dan in Oregon.

## “Brave, not perfect”

By Rachel George

I’m so glad I participated in the Kindergarten Inclusion Cohort because once I was in the first IEP meeting I realized how unprepared I would have been without it.

I’d met with our school district Special Services Manager and conveyed to her how important inclusion was to our family.

See “KIC” • P12

See “College” • P4



*Supporting the Down syndrome community has always been important to Donald and Mary Prescott. Mary's brother Donnie was born in 1948 with Down syndrome. He only lived to 14 months because of the lack of medical interventions or support available at that time.*

*Mary & Donald have an 11-year-old granddaughter named Eden who experiences Down syndrome and is thriving thanks to advantages that Mary's brother never had.*

*Mary has worked in Special Education for over 30 years and the Prescott family is dedicated to helping those with disabilities flourish.*

*Donald Prescott passed away in June, 2018. Mary has asked that memorial donations be made to NWDSA in his name. We wish to extend our deepest appreciation for this gift and our condolences for the family's loss.*

Dear NWDSA/ABI/NW Disability Support Community,

We hope your summer is kicking into gear, and we are looking forward to our upcoming Summer Social on August 12 and Buddy Fest NW on September 22.

Over the years it has been such an incredible experience to see our children grow and learn, find their own voices, and blossom into the unique individuals they were meant to be. At the same time, our community and organization has grown and matured. In addition to our initial and ongoing Reciprocal Learning Community trainings, we have grown to offer play groups, family socials, special education support drop-in hours, youth programs, Spanish-language resources, the immensely successful All Born (in) Conference, and Buddy Fest NW. There are also many advocacy and outreach projects we do that don't make headlines, but nonetheless are crucial to supporting our community both locally and nationally.

More recently we have been partnering with national and local organizations, colleges, and universities on the Think College initiative to advocate for inclusive post-secondary education opportunities for individuals with cognitive disabilities. It is very rewarding and exciting to see some of our teens freshly out of high school attending college!

Through all of this work, our core belief is that everyone belongs. Disability is a natural condition of the human experience, and to embrace diversity and difference will make our world a better place and help create opportunities for all people. Our community has and will continue to provide an example of inclusiveness and acceptance that is vitally needed.

I also wanted to ask for your continuing support for our organization. These are challenging times for non-profits, especially in securing foundation grants, and NW Disability Support is no exception. We are asking that our community help us overcome these challenges by committing to support us financially. You can make a one-time or recurring donation at [abicomunity.org/donate](http://abicomunity.org/donate). Another important way you can support our work and community is to register now for Buddy Fest NW at [buddyfestnw.org](http://buddyfestnw.org). Commit early to building your team, gathering pledges and donations, and registering all your friends and family. We look forward to seeing everyone at this amazing festival! Together we can make a difference and support our community as we move forward together.

Steven Holland, President



## World Down Syndrome Day Celebration

Every year on March 21, NWDSA celebrates friends, neighbors, coworkers, and loved ones who experience Down syndrome. Our 2018 celebration brought a diverse and raucous crowd to the Lagunitas Community Room. We drank beer and cider provided by Lagunitas, ate pizza, danced and sang, met characters from Star Wars, posed in the photobooth, covered ourselves with temporary tattoos, and partied with our community. Nick O'Donnell provided music and Arly Holzweissig favored us with tunes on her ukulele.



## 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. Some of the amenities and activities include bounce houses, live music, shaded areas and cool river water, games, food, and so much more. This event is free; RSVP is required. Don't miss it!

**SUMMER SOCIAL 2018**  
**SUNDAY, AUG 12TH**  
**12:30 - 3:30 PM**

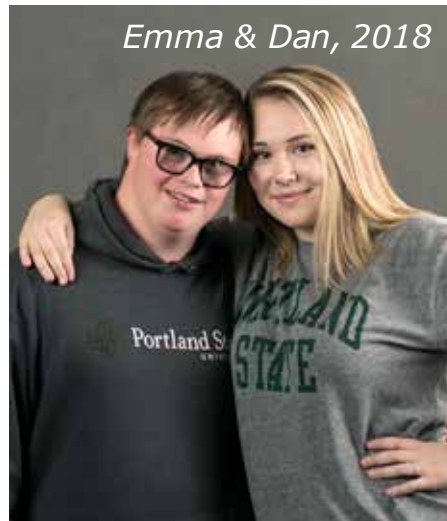
Camp Angelos  
 32149 SE Stevens Rd • Corbett, OR  
 RSVP Required:  
[abicommunity.org/events](http://abicommunity.org/events)

## College Cont...

Both Dan and Emma care deeply about inclusion in college and this created the charge to advocate for options for all students. At a meeting with Senator Ron Wyden, Dan pounded his fist on the conference table and said, "I want to go to college!"

In 2014, Dan and Emma stood together at a presentation at Portland Community College. Behind them stood a banner of a photo of them, captioned: "We share a dream of going to college". We have used the image to create real change for students with Intellectual disabilities.

Emma and Dan were key founding youth members of our organization's Think College Coalition and the partnership with Portland State University that helped



*Photo: Jeff Day*

develop the first four-year college option in Oregon for students with intellectual disabilities, as well as our Social Justice Youth Program. The powerful voices of these young adults echo those of Cody Sullivan and his friends at Concordia University where Cody recently finished four years of study in the Department of Education. [See page 5]

Two weeks ago, Emma and Dan posed for yet another photo—this time wearing t-shirts from Portland State University where they will both be attending in the coming year.

We have been alongside each other watching our kids grow and change and we are stronger for having mutual support for this journey. Our kids are also stronger for having each other and their shared belief in kindness, justice and their own worth.



We will be standing together at the 20-year anniversary of Buddy Fest NW and celebrating our successes with joy. Real dreams, hard work, and community matter. Looking forward to proudly walking with over 2,000 of you on September 22nd at the Moda Center.



*Emma & Dan, 2014*



*Photo: Eric Drapeau*

## Making History

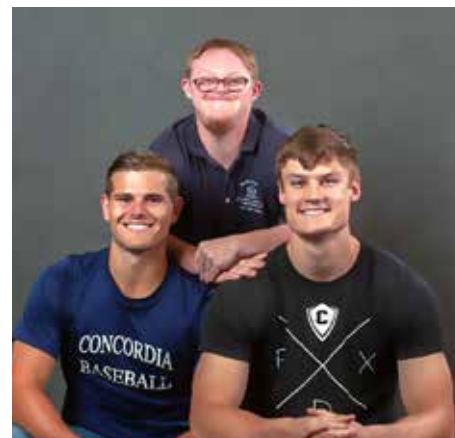
Cody Sullivan becomes the first student with Down syndrome to complete four years of college in Oregon

On Saturday, April 28th, 2018, Cody Sullivan walked in the Spring Commencement ceremony at Concordia University and became the first college student with Down syndrome to complete four years at an Oregon university. He received a Certificate of Achievement in the College of Education and has already secured a job as a kindergarten teacher's assistant at Kairos PDX.

In many instances, individuals like Cody are segregated from peers and typical instruction but Cody and his family worked hard to make sure he was included throughout his schooling, demonstrating how all students benefit from non-segregated classrooms, and that adaptive, inclusive learning environments allow a diversity of learners to thrive.

Through new programs at Portland State University and organizations like the Think College Inclusion Oregon Coalition, more secondary education opportunities are opening up to Oregonians for whom college was just a dream.

However, there is still a long way to go. Many universities in the U.S. don't offer a modified or accommodating degree for those with intellectual disabilities. The Think College Inclusion Oregon Coalition is dedicated to creating college opportunities for students with ID in Oregon.



*Photo: Jeff Day*

Cody with friends Matt Schweitz & James Phillips

*Matt and James are college classmates of Cody's.*

*The trio looks forward to the day when inclusion of people experiencing intellectual disability is the norm. They have experienced first-hand the strength of community and the positive changes in our lives when we learn, grow, and work together.*

*Cody, Matt, and James will be speaking about their college experiences at Buddy Fest NW 2018.*

Many parents of school-age children with disabilities aren't aware of high school graduation and diploma options in Oregon. It's important to understand the differences to best plan your family's future.

To learn more, visit the Oregon Department of Education website at [oregon.gov/ode](http://oregon.gov/ode).



## Buddy Fest NW 2017 Recap

Over 2,200 participants came to celebrate at Buddy Fest NW. Friends, family, and colleagues joined in support of loved ones and individuals around the world who experience Down syndrome.

Guest speaker Brandon Gruber got everyone cheering with his message of perseverance and independence. Parent advocate Leah Thompson shared her family's inspiring journey.

The Nu Wavers got everyone dancing with hits from the '80s, and emcee Tony Starlight kept the day humming along with humor.

Special thanks to FickelZeal Photography for the beautiful photos.



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

Campbell Global • Parker, Smith & Feek • Bike First! • Suzanne Goddyn, Windermere Real Estate • The Children's Clinic • Tillamook • Closetbox • Chubb Group of Insurance • Latitudes • Rose City Sound • FickleZeal Photography • Parties Inc. • Key Event Services • Sysco • Widmer Brothers • Nestle/Dreyers • Tony Starlight • Newell Briggs • The Nu Wavers • Hooperville USA • Central Catholic Cheerleaders • Portland Fire Department & Portland Police • All the volunteers!



## Dune buggy bandits inspire do-gooding

The pink and purple dune buggy that Alexis, a 7-year-old from Washougal, received for her birthday became one of her favorite toys.

Last year, the dune buggy was stolen from her family's front yard. The story received local news coverage as the family attempted to identify the thieves who had been captured on security camera.

As a result of the news coverage, many people within the community contacted Alexis' family and offered to donate money for a new dune buggy. Tammy—Alexis' mother—was grateful for the offers but asked people to donate to NWDSA on Alexis' behalf instead.

At Buddy Fest NW, Alexis and her family presented NWDSA with a check for \$500 from the generous donations of community members.

Thank you, Alexis!

Shout-out to our top fundraising teams:  
Bullwinkles, Soley's Bright Shine, Oliver's Goldfish, Team Dan, Archer's Team.



Top fundraising individuals: Shakyra Rosario, Eric Cerdena, Allen Scobba, Alice Miller, Shannon Larisey.



## All Born (in) Cross-Disability Best Practices Educational Inclusion Conference 2018 Recap

13th annual conference: "Building equitable and inclusive classrooms and communities. End segregation; our children can't wait!"

We are grateful for the 600+ parents, teachers, allies, and self-advocates who spent a beautiful, sunny Saturday with us.

David Pitonyak kicked off the conference with a keynote address that had everyone laughing, crying, and thinking.

Melody Musgrove shared strength and insights from her career spent advocating for inclusion.

A policy panel session featured five national policy and program experts—

Sharon Lewis, Melody Musgrove, Stephanie Smith Lee, Debra Hart, and Amber Smock.

The conference also featured a "Youth Track", with a series of workshops designed for members of our Social Justice Youth Program which is made up of individuals between the ages of 15 and 24, with and without disabilities. The day closed with the youths presenting 'Breaking Barriers' awards [read the story on page 16] to individuals who have gone above and beyond for community inclusion—Jan Zuckerman and Newell Briggs.

## Save the Date for All Born (in) Conference 2019

Apr 6, 2019 • Portland Airport Holiday Inn



### 2018 CONFERENCE PREMIER SPONSOR: Portland Public Schools

Multnomah Early Childhood Program

West Linn-Wilsonville School District • Clark County

Columbia Regional Program • Early Learning Multnomah • Independence NW • Oregon

Council on Developmental Disabilities • Concordia University •

Oregon ABLE Savings Plan • The Standard

Multnomah County • David Douglas School District

United Cerebral Palsy • FACT OR

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





*"David Pitonyak and Melody Musgrove were Amazing!! So much good info. The last session ... with Sharon, Melody, Stephanie and Debra, Amber. Sooo GOOD!!"*

*"Favorite thing ... Reconnecting with my inclusion roots. My training is in inclusion but I've been a pull-out teacher for so long that I've gotten a bit lost."*

*"The vast choice of topics allowed for people to engage at their preferred method of involvement. Political, social, educational & tech topics were all addressed."*

*"Batteries recharged to keep bustin' barriers to inclusion!"*





*Volunteers keep grassroots organizations like ours afloat. We are very grateful for all of the volunteers who helped with packet stuffing, data entry following the All Born (in) Conference, and so much more. Our gratitude for our "village" can't be measured!*



*Rachel, Maria, and Jamie—our New Parent Outreach dream team!*



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

Para padres que hablan español que tienen hijos con discapacidades.

Venga y conozca a otros padres quienes al igual que usted comparten la experiencia de tener a un hijo/ hija que experimenta alguna discapacidad. También es una oportunidad de conectarse a nuestros programas y recursos. Acompañanos!

Para más información, preguntas o detalles lláme al (503) 238-0522.

Locacion: Centro de Recursos • 11611 NE Ainsworth Cir, 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 who have children with disabilities.

Come and meet other parents who share your experience. It is also an opportunity to connect to our programs and resources.



### **SPECIAL EDUCATION SUPPORT DROP-IN HOURS SEPT THRU JUNE; BY APPOINTMENT DURING THE SUMMER**

Resources, tea, support, and advice • Every Thursday during the school year, and during the summer by appointment (call 503-238-0522)

Resourcefulness Center

11611 NE Ainsworth Cir, suite 321 • Portland, OR

"The Open Arms playgroup has become such an important part of my family's life. My husband and I started attending when my daughter Emma was only a few months old.

We love getting the opportunity to chat with other families and watching our daughter play with her friends. The Open Arms playgroup is a family; a community. I feel fortunate to be a member."

Kirstin Kuniyama



## NWDSA EVENTS

### SUMMER SOCIAL

**AUG 12 • 12:30 - 3:30 PM**

Annual summer get-together •  
RSVP required

Camp Angelos

32149 SE Stevens Road, Corbett OR

### BUDDY FEST NW

**SEPT 22 • 10 AM - 1:30 PM**

The biggest party of the year!

Rose Quarter Commons  
Main Amphitheater & Center Court

Register at [buddyfestnw.org](http://buddyfestnw.org)

**SEE INSERT FOR MORE INFO**

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

## ABI CROSS-DISABILITY EVENTS

### WORKSHOP: STUDENT-LED IEP MEETINGS

**OCT 18, 2018 • 6:00 - 8:30 PM**

More details coming soon.

MESD Auditorium • 11611 NE Ainsworth Cir • Portland, OR

### RLC WORKSHOP: HOPES, DREAMS & POSSIBILITIES: BUILDING ON YOUR CHILD'S STRENGTHS

**NOV 3 • 8:45 AM - 1:00 PM**

See page 13 for details.

Montavilla United Methodist Church • 232 SE 80th Ave • Portland, OR

### KINDERGARTEN TRANSITION 101

**JAN 19, 2019 • 8:30 AM - 1:00 PM**

Tools and tips for a great start to kindergarten • Designed for families of young children with developmental disabilities • Spanish-language track

MESD Auditorium • 11611 NE Ainsworth Cir • Portland, OR

### ALL BORN (IN) ANNUAL CONFERENCE

**APR 6, 2019 • 8:30 AM - 5 PM**

Save the date!

## OPEN ARMS MONTHLY PLAY GROUPS

We are excited to announce the expansion of Open Arms into Salem and Hillsboro!

For parents of children with disabilities age birth-5 and their families. Meet, share, snack, learn, and play!

### PORTLAND

2<sup>nd</sup> Tuesday every month

10:30 AM - 12:30 PM

Earl Boyles Elem School

10822 SE Bush St • Portland

Maria (habla Español)

(503) 238-0522

### VANCOUVER

1<sup>st</sup> Saturday every month

2:30 - 4:30 PM

Unitarian Universalist Church

of Vancouver • 4505 E 18th

St., Vancouver

Kirstin (541) 294-3873 or

Mayra (habla Español)

(509) 310-9905

### SALEM, SILVERTON & SURROUNDING AREAS

3<sup>rd</sup> Tuesday every month

10:00 AM - 12:00 PM

Silverton Indoor Park • 2nd

floor, Methodist Church • 203

W Main St., Silverton

Kara (503) 871-3636

### HILLSBORO

4<sup>th</sup> Friday every month

9:30 - 11:30 AM

Calvary Chapel Church • First

floor, room #102 • 6550 SE

Alexander St, Hillsboro, OR

Amanda (503) 473-3783

## KiC Cont...

The draft she sent me was 76% inclusion. After a 2-hour meeting and lots of back and forth, we ended up at 84%.

I wasn't prepared for how hard they clung to their goals. As we worked through each goal, I stated why I thought certain ones were unnecessary. They politely listened and then stated why they wanted it included. And then I countered with my suggestions and concerns, and they countered again. It seemed like they were listening to what I was saying but it wasn't their language. I felt that to get more goals removed I would have to be irate, and I erred on the side of preserving relationships.

The general feeling from the team was positive. When I asked them to change or add wording on a goal, they were quick to accept it. We had collaborated a lot, and they were visibly proud of the IEP we wrote. It was obvious that they didn't normally write inclusive, strength-based IEPs like this.

At an hour-and-a-half in, we went around and asked the service providers one-by-one if some of the services could be push-in instead of pull-out.

See "KiC" • P21



### Register now for 2018/2019 KiC

Nine-month-long program of interactive, best practices-driven trainings designed for parents whose child will be starting kindergarten the following September. Families receive in-depth trainings from educational and legal professionals in: Positive Behavior Supports, Special Education law, IEP goals to drive inclusive placement, and so much more

Learn more & apply at [abicomunity.org](http://abicomunity.org)

### Special thanks to KiC fundraisers

We'd like to extend our gratitude to Sizzle Pie, The Quality Bar, and Migration Brewing for their Beer Week fundraiser.

Our annual Toast to Inclusion winter event is always a great party and our biggest KiC fundraiser, bringing in vital funds for the program. Thanks to Lagunitas Community Room and other supporters for another successful event.



*Graduates from the 2017/2018 Kindergarten Inclusion Cohort armed with new tools to help them navigate the transition to kindergarten and advocate for an inclusive education for their children.*

## Los talleres de RLC ayudan a construir comunidad

by Yoisyveth Sarao

Mi nombre es Yoisyveth Sarao y tengo una hermosa bebé de un año con Síndrome de Down. Mis expectativas como madre cambiaron con la llegada de ella, trayendo a mi vida nuevas experiencias. Mis expectativas como mamá al principio fueron desastrosas, por el hecho de saber que fue diagnosticada con síndrome de Down, sin embargo ella ha traspasado todas las barreras sorprendiéndonos de gran manera.

Los entrenamientos de RLC han sido de grande ayuda para nosotros como familia. Nos han ayudado a formar parte de una comunidad que nos apoya y nos da ánimos para ayudar a nuestra hija Violeta a cumplir todo lo que ella se proponga.

Mi experiencia en el último taller fue de muchísima ayuda, me enseñó que ser paciente es la mejor clave para obtener los mejores resultados y que siempre existen mas de una forma de ayudar a nuestros pequeños a aprender.

### RLC workshops help build community

I have a beautiful one-year-old baby named Violeta with Down syndrome. My expectations as a mother at first were disastrous, yet my expectations changed since she has crossed all barriers to surprise us greatly.

The RLC trainings have been of great help to us as a family. They have helped us to be part of a community that supports us and encourages us to help Violeta to fulfill all that she sets out to do.

The last workshop was very helpful. It taught me that being patient is key to obtaining the best results and there is always more than one way to help our children learn.

### Register now for upcoming RLC Workshop: Hopes, Dreams & Possibilities: Building on Your Child's Strengths

**What:** Free, cross-disability session for parents & caregivers of children age 0-5 with disabilities

**When:** November 3, 2018 • 8:45 AM - 1 PM

**Where:** Montavilla United Methodist Church  
232 SE 80th Ave, Portland

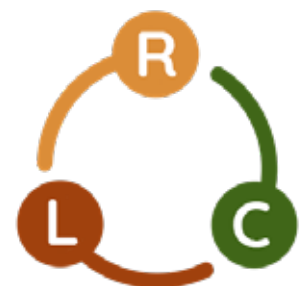
Please join us for a fun and interactive session exploring strategies to create a vision for the future. Including a panel of parents and experts.

- New families always welcome
- Spanish translation available
- Snacks & lunch provided
- Childcare available, space is limited, RSVP required

**Learn more & register at [abicommunity.org](http://abicommunity.org)**



*Yoisy and Violeta*



Reciprocal Learning Community  
FAMILY • COMMUNITY • EDUCATORS

## Rompiendo Barreras

por Maria Rangel

En Octubre del 2017 NW Disability Support, obtuvo fondos del Departamento de Educación de los Estados Unidos bajo el grant #H328C170012. Los fondos fueron asignados al plan de trabajo Rompiendo Barreras para la inclusión, con enfoque en la comunidad hispana.

Gracias al apoyo financiero que la organización obtuvo fue posible contratar a un miembro de equipo de trabajo bilingüe de medio tiempo. Como la nueva Coordinadora de alcance bilingüe, estoy trabajando para que los entrenamientos, eventos, recursos, apoyo para padres y conferencias sean más accesibles para nuestra comunidad de habla hispana.

Este año, en nuestra Conferencia anual All Born (in), pudimos aumentar la cantidad de material impreso disponible en español, así como también ofrecer el registro de conferencia en línea y información en español. También tuvimos dos sesiones presentadas totalmente en español, Esperanzas, Sueños y Posibilidades y Aspectos Básicos del IEP, a las que asistieron tanto padres como profesionales. En la sesión Esperanzas, Sueños y Posibilidades, compartí sobre mi camino de aprendizaje que me ayudo a ver más allá de la discapacidad de mi hija y cómo llegué a la mentalidad de desarrollar de sus habilidades para trabajar en la creación de una visión para su futuro.

Me gusta compartir la experiencia de mi camino que eh recorrido a través de ser la madre de mi hija que ahora tiene 12 años de edad que experimenta síndrome de Down. Siempre me gusta decirle a los padres nuevos, que sí tener una hija o un hijo que experimenta una discapacidad es diferente, pero eso no significa que tenemos que dejar ir nuestras esperanzas o sueños que tenemos para ellos, ya que su discapacidad solo es una parte de quien son nuestros hijos, mas no es una definición de todo lo que son. Ya que desearía que alguien me lo hubiera dicho cuando yo tuve a mi hija.

Me siento afortunada de tener la oportunidad de hacer este tipo de trabajo que eh hecho en los últimos 10 años porque si no la hubiera tenido, no sé si miraría el futuro de mi hija y vería un sinfín de posibilidades, como lo hago ahora. Mi objetivo para mi hija es que llegue hacer una persona adulta que navega, contribuye y es un miembro completo de su comunidad y que sea capaz de hacer y expresar sus propias decisiones.

[el artículo continúa en la página 22](#)





### Students create Seaside Walk for Awareness for Down Syndrome benefiting NWDSA, April 2018

Seaside High School student Shayla Tsuji and her classmates Autumn Dial and Jake Harold dedicated their Pacifica (senior) Project to help raise awareness for Down syndrome.

"We wanted to raise awareness ... and we thought a walk in our small town would be a great way to bring everyone together to educate about the reality of living with Down syndrome," said Shayla.

With the proceeds from the event, the group delivered a check for to NWDSA to support new parent outreach and awareness efforts.



*Summer 2018 saw another successful Bike First! Bike Camp. Riders of all ages, with and without disabilities, learned to ride traditional two-wheel bicycles and will go on to experience the joy and freedom of bike riding*

*Learn more at [abcommunity.org/bikefirst](http://abcommunity.org/bikefirst)*





*Photo: Ted Perkins*

*In April, 2018, NWDSA/ABI ally Alicia DeLashmutt [pictured with her mother Jane and daughter Neva] was featured in Hollywood Star News, highlighting her work with Our Home: Inclusive Community Collaborative, whose mission is to provide, promote, and educate regarding the need for diverse, inclusive communities. Find the full article at [star-news.info](http://star-news.info)*

*In May of this year, KGW did an extensive piece exploring West-Linn Wilsonville School District's successful efforts to create a 100% inclusive school environment. West-Linn Wilsonville School District is an All Born (in) Conference partner and presents a workshop at the conference every year sharing their excellent work and the tools and techniques that go into cultivating an inclusive school. Find the full article and video at [kgw.com](http://kgw.com).*

## Breaking barriers to inclusion: ABI's Social Justice Youth Program presents a special video project

by Joni DeRouchie

**This is a story about a video about a voice mail about a demolished institution but is actually about so much more...**

A few months ago, Angela Jarvis-Holland, NWDSA/ABI Executive Director, received a voicemail from her friend and inclusion ally Sam Sennott. Sam was in Salem, OR for a conference and learned that demolition teams were tearing down the last remaining buildings of Fairview Training Hospital and Center—a once-booming state institution for individuals with developmental disabilities.

After decades of imprisoning "inmates", many of whom were children, and countless instances of abuse and human rights violations, Fairview closed its doors permanently in 2000. Nearly 20 years later, final demolition of the remaining buildings began. Compelled to see the demolition for himself, Sam visited the grounds of Fairview to watch the last of the walls fall. Moved by what he saw, Sam called Angela and left her a heartfelt message about the experience.

Angela shared the voicemail with her husband Steven and her 19-year-old son Daniel, who experiences Down syndrome. Steven suggested they visit Fairview to see the demolition. Dan's friend Eddie, who also experiences Down syndrome, came along.

They got in the car and headed for Salem. On the way, Angela asked Dan and Eddie if they would like to watch an old newsreel film about Fairview, warning them that it showed images of kids like them living in horrific conditions.

**See "Fairview" • P20**





## Social Justice Youth Program Summer Camp

Young adults from age 16-25, with disabilities and without, spent three days on Portland State University's campus exploring creative avenues for activism. Through collaboration and support, and with the contributions of leadership mentors from the community, campers created visual art, t-shirts, music, comics, and much more. They slept in dorms and experienced campus life as they learned about each other and how to work together towards common social justice goals.

This August marks the third Social Justice Summer Camp as the program continues to grow. Topics of music composition, sexuality, broadcasting, photography and videography, and much more will be explored with local artists, educators, and community leaders.

Learn more about how you can contribute or donate to the Social Justice Youth Program at [abicomunity.org/youthcamp](http://abicomunity.org/youthcamp)



*[above] NWDSA/ABI Program Director Angela Frome & Social Justice Youth Group member Dan Jarvis-Holland accept a donation from Independent Order of Odd Fellows #128. With this gift, we were able to offer scholarships for the Summer Camp program.*

*[right] This year, the annual All Born (in) conference included a specialized youth track, with workshops featuring national advocates Keith Jones and Amber Smock. Upon completion of the youth track, the group posed with their 'graduation' caps.*



## Finding friends and support at Buddy Fest NW

by Molly Hulett

I remember vividly attending our first Buddy Walk (now Buddy Fest NW). We were scared, overwhelmed new parents of a 2-month old baby named Parker who experiences Down syndrome. Parker was born with pulmonary hypertension and needed oxygen for the first few months of his life. We hopped the Max headed to Buddy Fest NW and, as the train took off, we opened ourselves up to a new journey and something that would eventually represent close friends and family support.

Today, we had an epic birthday party, as we do every year. I never know how many kids will come but each year it grows. It's amazing to see the friendships that inclusion have developed for Parker, and how much his friends and peers value and respect him. Tonight Parker read most of his birthday cards on his own and I had to breathe deeply in order to maintain my composure.

Is this journey perfect? No. But when we get beaten down by the system or individuals, we choose to rise up and let our family's values and beliefs lead the way.

Inclusion and community are everything and we would not be on this journey without the support of programs funded by donations raised at Buddy Fest NW. Parker's Pirates will be there again this year and we hope to see you there!

## A day of community and love

by Mindy Parker

Our family's first Buddy Fest NW was in 2010, after the birth of our second daughter. We spent most of the day on the lawn, taking it all in and enjoying the family and friends that came along to enjoy the day with us. My oldest friend made team hats to officially announce Team Nickel's Pickles. From there, we increased our participation year by year, and eight years later, my family has the date saved well ahead of time, and our friends and family are quick to participate. This will be our ninth walk this year and each year Nickel grows more eager to attend. Last year she was just a few steps shy of completing the entire walk on her own two feet. While I'm not sure that experiencing Down syndrome really resonates with her yet, she definitely recognizes that this is a day of family, friends, and fun, and I am ever thankful for the opportunity to share such a day of community and love with her and all the other families and supporters in our area who experience and embrace Down syndrome.



This year is all about celebrating milestones, including 20 years of bringing the biggest party for "buddies" to Portland!

**See the insert for more info about Buddy Fest NW 2018**



## Expanding inclusive college options in the Northwest

by Jamie Burch

Last year, Think College—the national organization dedicated to improving inclusive higher education options for people with intellectual disability (ID)—awarded NW Disability Support a capacity grant to do regional work through our West Coast Think College Coalition, developing and expanding inclusive college options in the Northwest. The funding supported continuing the work which, in partnership with Portland State University, led to Oregon’s first inclusive higher education program. There are currently very few choices available for college-bound students with ID in Oregon, Washington, Idaho, and northern California as compared to other areas across the country. Some of the available local programs segregate students with disabilities and do not give them the opportunity to participate in the same courses as students without disabilities, or are only open to students with select diagnoses considered high-functioning.

In September 2017, we held a two-day regional training for about 40 youths, parents and professionals. The youth voice—including those with disabilities and their non-disabled peer supporters—collectively asked, “Why not me?” when discussing college dreams for individuals with ID. Parents and professionals learned how to amplify the youth voice, work together to advocate for more post-secondary programs, and support the dream to make inclusive college a reality.

In April 2018, supported by a City of Portland grant, we hosted a one-day regional training called Opening Doors to Inclusive College Options. Over 70 youths, parents, and professionals explored inclusive post-secondary best practices and collaborations. Again, the voices of the youths sent a strong and proud message: “We should not have to fight to get into college.”

We believe that college should be an option for everyone who is interested in pursuing it. Recent findings show that individuals who completed TPSID-model (Transition and Post-secondary Program for Students with Intellectual Disability) programs at college and university campuses had higher employment rates, higher satisfaction with their social lives, and some were living on their own with roommates or a significant other. Read the results of the study at [thinkcollege.net](http://thinkcollege.net).

As the Think College hub in the Northwest, we provide support and assistance to youth, parents, professionals, and inclusive college advocates through resources, information, and a support network. Having post-secondary options for students with ID is a new and growing movement and you can join us to be part of it. It is work that I am personally invested in, as my teenage daughter wants to go to college, but there are no options available to her in SW Washington.



## Fairview cont...

Angela explained that understanding the history of how individuals with developmental disabilities were treated in the past is important but can sometimes be upsetting. Dan chose to watch the film; Eddie declined.

When they reached Fairview, Angela and Steven took photos and videos of Dan and Eddie exploring the grounds. Dan leaned against a gated fence and spoke about the shame of Fairview. Dan said that learning about the survival of kids like him in Fairview makes him want to be a strong man and a strong advocate. Angela was deeply moved to see her son leaning on the gate and speaking about being a "strong man" knowing that, had he been a Fairview "inmate", he would never have been able to pass through that very gate.

The family collected pieces of rubble from the demolished buildings of Fairview Hospital to bring home as reminders of the history and progress of disability rights. As they were leaving the grounds, they approached the sign at the entrance—now covered with boards and concrete.

They remembered that they had a bucket of chalk in the car. Their parting gift to Fairview was the words "Free Our People" written in giant chalk letters where Fairview's sign used to be.

Later, Angela shared the photos and videos, as well as Sam's voicemail, with members of the Social Justice Youth Program. The group had the idea of creating a video out of the footage and photos.

Members of the Youth Program wanted to know more about the history of disability rights. They recorded additional footage, including interviews with Dan's brother Quinn and disability rights historian Michael Bailey.

What the group noticed is that, while it's true that the civil rights of individuals with disabilities have come a long way, many 'invisible barriers' to inclusion remain and individuals like Eddie and Dan face these barriers nearly every day.

Youth Program members recorded footage of the group discussing invisible barriers and their hopes for the future.

At the conclusion of the Youth Track at the 2018 All Born (in) Cross-Disability Educational Inclusion Conference in April, the group premiered their video to rave reviews from the 600+ attendees.

**See the video:**

<http://bit.ly/BreakingBarrierstoInclusion>



*The final piece of the story—Social Justice Youth Program members created awards out of the pieces of rubble that Dan collected from Fairview. To close out the ABI Conference, the group presented these "Breaking Barriers" awards to members of the community who advocate for inclusion and make a difference in a real way.*



*Dan presents the award to his former teacher Jan Zuckerman. An award was also given to Newell Briggs, a years-long ally and beloved friend of the NWDSA/ABI community.*

## KIC Cont...

Service settings were negotiated for more push-in, but everyone was very slow to do so. The principal took a pause to say, "I think we all can agree that this student needs a 1:1 all day." Immediately, the two kindergarten general education teachers piped up and said, "Yes, we do, too." I let the talking die down and said, "I don't feel comfortable agreeing to full time para support unless we have a fade out plan."

The option presented was to increase inclusion time by declining some of the related services. I was on the fence because it is important for rapport to be built with my daughter, so we decided to see how the first few weeks of school go. I asked to schedule a meeting in November to adjust the IEP if needed after parent/teacher conferences.

I'm proud of the tone I set—checking every detail, speaking my mind, and building working relationships. I do wish the percentage of inclusion for my child was higher. I wasn't prepared for feeling so mixed, but truly it is a preview of the next 15 years. The biggest takeaway is that my foremost challenge will be educating each team member individually, and in their own "language" about how and why inclusion is truly best practice. They are absolutely still operating in the old paradigm of "special services in a separate setting is where special kids learn best."

There's a saying I heard that really rings true with advocacy: "Brave, not perfect." I've been trying to take it to heart. We've started the journey and that's the hardest part. We have to keep going and not worry about being perfect at it.

## Letter to a science teacher from a high school sophomore

*Thank you for being open to hearing more about the new law and diagnosis language for people with intellectual disabilities (formerly mental retardation). This issue is close to my heart because I am involved in a social justice youth group, my mom is a professional in the intellectual disability field, and my sister—who is a funny, smart, eighth grader—also happens to have a cognitive disability.*

*Even though some professionals still use the term MR it is no longer current or respectful terminology. I would like to share the following resources with you regarding today's standards for language regarding people with intellectual disabilities in law and medical diagnosis, as well as language around people with Down syndrome, and a respectful language concept called People First.*

*I share this information with you because your students look to you to learn facts and will model the language and perspectives you teach. The words we use when referring to people with disabilities are important to me, people with disabilities and their families, and the disability rights movement. Words matter and shift our thinking. Current and respectful language will make our society more inclusive, and move us forward towards equal rights and equal opportunities for people with disabilities.*

*I know change takes time. My little sister and I would greatly appreciate your support in creating awareness and acceptance.*

*Thank you so much,  
Claire Burch*



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

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Editor, Production, Design: Joni DeRouchie

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

### Rompiendo cont.

Me siento muy bendecida no solo por tener una comunidad que apoya mis objetivos, sino porque también tengo la oportunidad de trabajar con personas que me han ayudado a aprender, crecer y comprender muchas cosas diferentes. Y si yo tengo la bendición de tener esto, entonces quiero ayudar a los padres a tenerla también para que juntos podamos crecer y apoyarnos mutuamente a través de nuestras experiencias.

### Breaking Barriers

by Maria Rangel

In October 2017, NW Disability Support was awarded funding from the United States Department of Education under the grant #H328C170012. The funds are assigned to the work plan "Breaking Barriers to Inclusion" with a focus on the Hispanic community.

Thanks to the funding, the organization was able to hire a part-time bilingual staff member. As the new Bilingual Outreach Coordinator, I am working to make trainings, events, resources, parent support, and conferences more accessible to our Spanish-speaking community.

This year at our annual All Born (in) Conference, we were able to increase the amount of printed material available in Spanish, as well as offer online conference registration and information in Spanish. We also had two sessions presented in Spanish only—Hopes, Dreams and Possibilities, and IEP

Basics—that were attended by both parents and professionals. In the Hopes, Dreams, and Possibilities session I shared my journey of learning to see past my daughter's disability and how I got to the mindset of building on her abilities in order to work towards creating a vision for her future.

I really enjoy sharing the experiences I gather through my journey of being mom to my now 12-year-old daughter who experiences Down syndrome. I like to tell new parents, "Yes, having a child that experiences a disability is different but that doesn't mean you have to let go of the hopes and dreams you have for them, because their disability is just a part of who they are not a definition of all they are." I wish someone would have said that to me when I had my daughter.

I'm so glad that I landed in this type of work for the last 10 years because if I hadn't, I don't know that I would look at my daughter's future and see endless possibilities like I do now. My goal is that she grows into an adult that navigates, contributes to, and is a full member of her community, and that she is able to make and express her own choices. I feel very blessed to not only have a community that supports my goals, but also to work with people that have helped me learn and grow. I am blessed to have that and I want to help parents have it too, so that together we can support each other through our journeys.



*The Lion Forge LLC*

*We'd like to give a special shout-out to local writer David Walker and Bridge City Comics. David co-writes Superb, published by Lion Forge LLC, which features the first ever comic book superhero who experiences Down syndrome. In August, 2017, Bridge City Comics hosted a signing event with David and donated a portion of every sale to ABI's Social Justice Youth Program.*

*David Walker also brought his skills and knowledge to our 2017 Social Justice Youth Summer Camp. He led a workshop for the campers and inspired them to express themselves through comic art.*

*David reflects, "The workshop was an incredible experience, and the young people that I met were absolutely amazing. There was so much creativity and positive energy in that group that it reinvigorated my soul."*

Northwest Down Syndrome Association and ABI are programs of NW Disability Support [[nwdisabilitysupport.org](http://nwdisabilitysupport.org)]

#### 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.

Each board member 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 consists of volunteers and is supported by enlightened professionals.

**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.

**NWDSA**

northwest down syndrome association

**(abi)**

community

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Articulos en Español dentro del boletin!

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**Be sure to check out our new websites**

**abicomunity.org**  
Find information about all of our cross-disability programs, news, and events—including the All Born (in) annual conference

**nwdsa.org**  
Learn about our Down syndrome programs and resources—including *New Parent Guides* and *Healing Heart* booklets

**buddyfestnw.org**  
Register for Buddy Fest NW, create or join a team, or donate year-round

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

