

STEPPING UP

News from ABI & NWDSA • Programs of NW Disability Support

ISSUE 31 • FALL 2021

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Buddy Fest Past, Present, and Future

By Angela Frome

Every fall for the last 23 years, and I have been to every one, the Northwest Down Syndrome Association (NWDSA) has kicked off Down Syndrome Awareness Month with our annual Buddy Fest celebration and walk to promote acceptance and inclusion of all people with Down syndrome. This year, we held our second live virtual event to mark the important day, share the pride of our community, and have some fun. A big thank you to participants, top teams, board, supporters, friends, and the community who worked hard to help us work towards our goal. We enjoyed a live-streamed walk together, a stroll down memory lane, and a beautiful sunny day.

Thinking of years past, I missed standing in the plaza at the Rose Garden just before the sun came up, enjoying a moment of peace and silence, and anticipating the hundreds and hundreds of smiles and beautiful faces that would soon take over the space.

Buddy Fest NW brings together families, friends, self-advocates, educators, professionals, community leaders, and other promoters of a civil and inclusive society for a day of community, fun, and a big, old family reunion. Our festival shines a light on our self-advocate leaders as they share about their journey, dreams, important contributions, and welcome over 2,000 participants from Portland metro and Southwest Washington. Small babies to adults, families and friends, teachers and medical professionals, corporate teams— everyone is welcome to join in on this day celebrating diversity and inclusion.

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NWDSA
northwest down syndrome association

all born (in)

A letter from our Executive Director

We are almost at the end of another year, and I hope this newsletter finds you well, and looking forward to some of the celebrations ahead!

I admit to deeply missing our organization's in-person celebrations and gatherings. World Down Syndrome Day, Summer and Winter Socials, our ABI conference, and Buddy Fest are places where I feel connected and part of a family. Those events help us to feel less isolated and part of an amazing circle of allies who believe in people with disabilities and share high expectations for real lives in community. I am proud that despite the shift to virtual work, we have been able to continue working on education, supporting disability rights and dignity, and keeping our families' needs visible in these complex times. We have also managed some music, smiles and laughter on our Facebook page, a second virtual Buddy Fest, and youth zoom calls that allowed our young people to stay connected.

We would usually be planning for our winter holiday event at this time of year, and my thoughts are back to a winter social almost ten years ago, where we were having fun at a community center. We had a Santa, food, music, and all the usual things that create smiles.



We also had a table set up on the stage with a pile of votive candles. The family with the youngest baby lit a candle and placed it in the center, and then every family lit another candle, making a big circle of light. It has been a challenging year for us all, and yet we are still a part of a circle, and stronger together even while apart.

So when I light the candles I love in my home during the holidays, one of them will be with all of our families in my mind. I am grateful for the purpose and mission that guides my work, and for the dedicated staff and board I work with. Thank you for the ways you support our organization, and from my family to yours, I wish you peace and good health.

Angela Jarvis-Holland

TOP BUDDY FEST TEAMS 2021:

1. Bullwinkle
2. Daniel Jarvis-Holland
3. Disney-Bound and Down
4. Board Buddies

Buddy Fest Past, Present, and Future Cont...

The day is a big party with a sea of the beautiful color of Buddy Fest shirts, smiles, pride, hugs from new friends and old ones, and a real coming together. When I think back over the years, I reflect on those special moments when a new family comes for the first time and feels they are a part of the community and connected. Buddy Fest holds a special place in my heart, honoring those first steps, celebrations of successful surgeries, recognition of the youngest babies, and those walking in memory of someone they love.

I am looking forward to better days to come, and get excited thinking ahead about future events and all the fun games, bounce castles, raffle/silent auction, food & drink, and entertainment galore! A dance party with our wonderful entertainers is bound to happen, along with hula hoopers, cheerleaders, Star Wars characters and much more to bring joy to the day.

Buddy Fest not only brings together our community with old friends and new, it's also our biggest fundraiser of the year, supporting the vital work of NWDSA, including a New Parent Guide, new parent outreach and ongoing support; training on child development, assistive technology, state and county programs and more; the Healing Hearts booklet; family socials, Stepping Up Newsletter; and our Resourcefulness Center.

While we wrapped up October's Down Syndrome Awareness month a month ago, let's continue every month to keep shining the light on the amazing contributions people with Down Syndrome bring to our communities everyday! We are sure missing you all like crazy and cannot wait to party again in person.

We want to give a big shoutout to Joni Derouchie for production, Abby and Adara for their amazing spirit and funny antics and creativity, and to our wonderful Emcee Kristin Behlings and musician Nick O'Donnell. It was nice to see beautiful faces, connect with old friends and new, and shed a tear of joy or two!

Be well my friends.



¡La inclusión funciona!

By Yoisy Sarao

Cuando piensas en el futuro de tus hijos, lo que más deseas es que el camino no sea difícil, tanto como para ellos como para ti. Sin embargo, como padre de un niño con discapacidad, las cosas no siempre son así. Para nosotros como familia, la opción de educación especial era un poco difícil de aceptar, y cuando el tiempo de iniciar la escuela llegó, estábamos dispuestos a apoyar a Violeta en lo que más pudiéramos para que lograra el éxito, y pues también tenemos grandes sueños para ella. Después de haber asistido a grupos de apoyo, entrenamientos y de ser parte de NWDSA, nos sentíamos listos. Pero el día llegó y Violeta fue puesta en clases de educación especial, porque el distrito escolar que nos tocó no ofrece algún programa inclusivo para ella. Al principio nos sentíamos un poco derrotados porque pensábamos que no estábamos abogando lo suficiente por ella para que las cosas cambiaran y ella pudiera ser parte de un programa inclusivo. Queríamos que ella iniciara su vida escolar siendo parte de un salón inclusivo, pero no fue así. Así que nos pusimos a la tarea de asegurarnos que esa opción aún fuera posible. Gracias al apoyo de NWDSA/ABI y a que nuestra visión para Violeta es que ella pertenezca. Este nuevo año escolar Violeta ha logrado entrar a uno de los primeros programas, inclusivos de nuestro distrito. No fue fácil, pero gracias a todo el apoyo de otros padres de la comunidad y a las ganas de ver a nuestra hija triunfar, hemos logrado ser parte de este programa el cual hasta ahora ha sido muy beneficioso para ella y sus compañeros de clase.



Inclusion Works!

By Yoisy Sarao

When you think of your kid's future, the last thing you want is for the road to be difficult, not only for your kids, but for yourself too. However, being a parent of a child with a disability, chances are things will get difficult at times. For our family the special education class option was hard to accept when the time for school finally arrived, and we were willing to support Violeta as much as we could for her to succeed, and we have big dreams for her. After being part of support groups, trainings, and the NWDSA, we thought we were ready. But the first day of school came and Violeta was assigned to a special education classroom, since the school district we belong to didn't have an inclusive program for her. At first, we were a little devastated. We thought we were not doing enough to advocate for her so she could be part of an inclusive program. We wanted her school life to begin in an inclusive setting, but it wasn't like that. So we put all our efforts to make the change and make sure there was an inclusive option for her. Thanks to the support of NWDSA/ABI, and to our vision for her to belong and be part of inclusion this new school year, Violeta is part of one of the first inclusive programs in our district. It wasn't easy, but thanks to all the support from other parents in our community and our vision for her success, we've made it happen and it has been so beneficial for her and her classmates.

NWDSA and ABI are programs of NW Disability Support

Board of Directors

Steven Holland
Abigail Braithwaite
Angela Jarvis-Holland
Guiseppe Lipari
Michael Rosen
Johnathan Cotton
Molly Hulett

Executive Director

Angela Jarvis-Holland

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

Vaccines with Care

By Angela Frome

All Born In is one of the few disability-focused community based organizations helping the Oregon Health Authority around Covid 19 information and awareness, and vaccine information. Our team understands disability and how to get creative to meet diverse needs. Here's a great example.

We had a family come to our event on their seventh attempt to get a COVID vaccine for their lovely, full-of-life 15-year-old-girl who experiences a disability. Our team spent some time with dad to find out what his daughter liked, what her needs were, what motivates her, and how we could make this the quickest, best experience for all. We had all the paperwork and vaccine ready to go before she got out of the car. We worked out that she loves stuffed animals, sparkles, and a good party, and is always motivated by a shout-out. We had a big stuffed unicorn she got to keep, had a bubble machine going, and worked with the vaccine team to come to the make-shift party tent and vaccinate the girl standing up. The parents gave her a big family group hug, and our team gathered around her while we cheered, blew bubbles, clapped and she got the poke. It was over super fast and she herself was so excited she did it. She also took away a copy of our Beating Covid comic which she loved and which helped her prepare for her second vaccine.

This experience was an incredible relief for the family, and they were so excited to come back to our next event to get her second dose, and this time she came back knowing what to expect and looking for her vaccinator friend, Diendre. This second shot went smoothly and was a huge success. We so appreciated the creativity and openness of this team to just roll with us. When the little ones start getting vaccinated it will be great to have lots of support and creativity.

We wanted to give a shout-out to the Multnomah Learning Academy team for being our vaccine partners, offering outreach to the community. Thank you Sheri Fitzsimmons, Ann Donaca and team!



Hospital Support Persons

NWDSA helped fight for Senate bill 1606; These are your rights.

A person with a disability has a right to a support person* if they are in an emergency department or admitted to a hospital. At this time, COVID-19 is forcing many hospitals to limit or not allow visitors. However, by state law, hospitals will welcome support persons for patients with disabilities. Visitors and support persons are different under Oregon law.

Support persons assist patients with disabilities who are admitted to the hospital or are in the emergency department who need help:

- Communicating
- Making health care decisions
- Understanding health care information, or
- Engaging in daily living activities

Eligible patients or their legal representatives can designate at least three support persons. Hospitals must allow eligible patients to have at least one support person with the patient at all times if necessary to facilitate care. Visitor hours do not apply to support persons. A hospital may have safety conditions such as limiting the number of support persons allowed to be present with the patient at a time.

Support persons must follow safety standards to serve in this role, such as wearing a mask and taking other precautions that may include but not be limited to handwashing and social distancing.

If a patient's request to have a support person present is denied or limited, including limits on the total number of support persons allowed to be present during the course of a day, the patient or support person can request a support care conference to discuss this decision with hospital staff.

If you or your support person has additional concerns, you can:

- Email the Oregon Health Authority COVID-19 Feedback Team at covid.19@dhsoha.state.or.us.
- Call the Oregon Health Authority COVID-19 Feedback Team at 503-945-5488.
- Contact Disability Rights Oregon at 503-243-2081.

"Support person" means a family member, guardian, personal care assistant or other paid or unpaid attendant selected by the patient to physically or emotionally assist the patient or ensure effective communication with the patient.

Personas de apoyo en los hospitales

NWDSA ayudó a luchar por el proyecto de ley 1606 del Senado; Estos son sus derechos.

Una persona con discapacidad tiene derecho a una persona de apoyo * si está en un departamento de emergencias o ingresada en un hospital. En este momento, COVID-19 está obligando a muchos hospitales a limitar o no permitir visitantes. Sin embargo, según la ley estatal, los hospitales darán la bienvenida a personas de apoyo para pacientes con discapacidades. Los visitantes y las personas de apoyo son diferentes según la ley de Oregón.

Las personas de apoyo ayudan a los pacientes con discapacidades que ingresan en el hospital o están en el departamento de emergencias y necesitan ayuda:

- Para comunicarse
- Tomando decisiones sobre el cuidado de la salud
- Comprendiendo la información de atención médica, o
- Participar en actividades de la vida diarias

Los pacientes elegibles o sus representantes legales pueden designar al menos tres personas de apoyo. Los hospitales deben permitir que los pacientes elegibles tengan al menos una persona de apoyo con el paciente en todo momento si es necesario para facilitar la atención. El horario de visitas no se aplica a las personas de apoyo. Un hospital puede tener condiciones de seguridad como limitar el número de personas de apoyo que pueden estar presentes con el paciente a la vez.

Las personas de apoyo deben seguir los estándares de seguridad para desempeñar este papel, como usar una mascarilla y tomar otras precauciones que pueden incluir, entre otras, el lavado de manos y el distanciamiento social.

Si la solicitud de un paciente de tener una persona de apoyo presente es negada o limitada, incluyendo el límite del número total de personas de apoyo que pueden estar presentes durante el transcurso de un día, el paciente o la persona de apoyo puede solicitar una conferencia de atención de apoyo para discutir esta decisión con el personal del hospital.

Si usted o su persona de apoyo tienen inquietudes adicionales:

- Envíe un correo electrónico al equipo de opiniones y comentarios de COVID-19 de la Autoridad de Salud de Oregón a covid.19@dhsosha.state.or.us.
- Llame al equipo de opiniones y comentarios de COVID-19 de la Autoridad de Salud de Oregón al 503-945-5488.
- Comuníquese con Disability Rights Oregon al 503-243-2081.
- Comuníquese con NW Disability Support al 503- 262-4029.

* Persona de apoyo" significa un miembro de la familia, tutor, asistente de cuidado personal u otro asistente pagado o no pagado seleccionado por el paciente para ayudar física o emocionalmente al paciente o asegurar una comunicación efectiva con el paciente.

Healing through Community

By Anna Herbig

Getting emails from new or expectant parents has brought me such joy during this solemn time. The pain, uncertainty and loss many have experienced these past couple years feels insurmountable. While we continue to grieve for what was and is lost, we must keep on rebuilding.

There is such promise, possibility and hope in young life. A few weeks back, I was helping a new parent get in touch with early intervention and while writing down contact information I realized I recognized their name. During that process I got to speak with some members from my daughter's old school team. We walked down memory lane for a bit, and then I was able to share where my daughter Hattie is now. It was wonderful to connect after so many years. It reminded me of how far Hattie has come, and I'm excited for what the future has in store. Although we all greatly miss face-to-face connections, we must continue to stay healthy and safe for our most vulnerable, youth.

In the meantime we will keep making the most out of Zoom, phone calls and email. Please keep the updates and photos coming. They make my day! Please join us in welcoming our newest members: the Ahina family, the Ellison family, and the Sprute family! Theo's parents Vanessa and Andrew share that they've come to realize Down syndrome is about community and love, and I couldn't agree more!

If you or someone you know is a new parent seeking advice and support visit nwdsa.org/get-support.



THIS HOLIDAY SEASON...



**OUR GOAL IS TO RAISE
\$50,000 FOR OUR
RESOURCEFULNESS CENTER**

This year, from Giving Tuesday, on November 30th, through December 31st, we're raising money to support our Resourcefulness Center, which directly serves our community.

**80% OF OUR
CONTRIBUTIONS ARE \$100
AND UNDER**

We will be lighting a new candle every time we reach a fundraising benchmark, and by January 1st we hope to have a beautiful holiday array.

**IF EVERYONE ON OUR
MAILING LIST DONATED \$20,
WE WOULD REACH OUR GOAL**

When we say your small gift leads to big change, we mean it! Our small, staff is driven by the mission to keep the rights and dignity of people with disabilities visible, relevant, and sustainable.

**WE BELIEVE OUR WORK IS MEANINGFUL. CONSIDER HELPING US REACH
OUR GOAL BY DONATING EITHER:**

- **ONLINE AT [NWDSA.ORG/MAKE-A-DONATION](https://www.nwdsa.org/make-a-donation)**
- **OR MAILING BACK THE ATTACHED ENVELOPE.**

THANK YOU

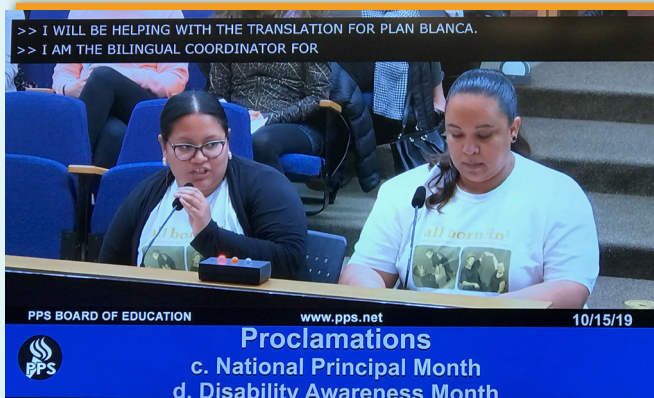
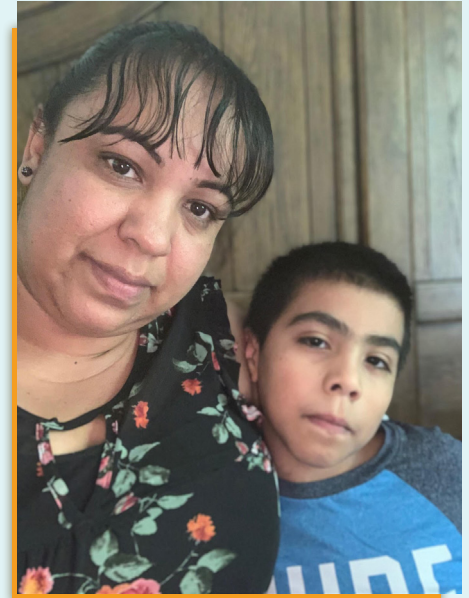
WHAT THE RESOURCEFULNESS CENTER PROVIDES

The NWDSA/ABI Resourcefulness Center is a place where one phone call can spark change, not just in the lives of the families who call, but in ways that spread light across the entire community.

Take the story of Blanca Orozco, as shared in the Summer 2020 issue of Stepping Up. After watching her family's dream for her child begin to be squashed by segregated school placements and an education system not set up to meet the needs of a bilingual family, Blanca reached out to NWDSA/ABI for support. Our staff worked with Blanca to help her advocate for what was best for her son, and in Blanca's words, this **"was when I began to understand the rights of my child, and my own rights as a mother within the Special Education system."**

In the end, Blanca was able to successfully advocate for her son to return to his neighborhood school, supported in the general education classroom, where he soon began to thrive.

But that's not where the story ends. The lighting of the inclusion candle for Blanca and her family is an amazing illustration of the power of the NWDSA/ABI Resourcefulness Center team.



Thanks to Angela Jarvis-Holland and Angela Frome's deep relationship with Portland Public Schools, and the work of Bilingual Outreach Coordinator Maria Rangel and Projects and Community Coordinator Jamie Burch, we were able to effect change at a systems level with lasting impact for all families.

Over the months leading up to and following Blanca's call, other families reached out to the Resourcefulness Center looking for support with similar struggles around language barriers and equitable access. Over

the course of several months, we brought these families together and provided support and information through a series of powerful gatherings.

We invited the school district leadership to sit at the table for a shared meal hosted by the families, and collectively advocated for PPS to create a position for a Bilingual Special Education Family Engagement Specialist. This vital role reduces barriers to families across the district, and it all started with one parent looking to support her child, and then reaching out a hand to her community to make change for all.

Your gift to our end of year campaign will help us continue to offer this type of personalized support to families, while actively working to promote the inclusion, empowerment, and civil rights of people with developmental disabilities.



Representing at Rose City Comic Con!

On September 10th, Angela Frome, Angela Jarvis-Holland, Shannon Wheeler, Martin Thomas, Maria Rangel, Daniel Jarvis-Holland, and I gave the presentation "How to Turn a Pandemic into a Great Comic" at the Rose City Comic Convention.....

We emphasized that we created an accessible and fun way to present the issues around COVID to all audiences, and that comics were written in both English and Spanish.

Plus our Youth Group kept our work grounded in reality. They insisted on the portrayal of a modern wheelchair for our hero!



By any measure, the comics were a success, with over **170,000** issues distributed throughout Oregon and Washington!!!

Grants from both the Oregon Health Authority and Washington Department of Health provided the funding to create and distribute the comics.

You can watch the entire panel on our YouTube channel, <https://www.youtube.com/user/nwdsa>

Mike Rosen

Nuestro trabajo continúa

By Maria Rangel

Los últimos dos años han sido muy difíciles para todos y nos hemos tenido que enfrentar a diferentes barreras, debido a la pandemia. Y para nosotros en NWDSA/ABI también ha habido barreras. Pero gracias a la tecnología y a nuestros esfuerzos hemos podido continuar nuestros apoyos a través de zoom, correo electrónico y por teléfono. Y a través de estas plataformas hemos podido continuar nuestros apoyos como apoyo individual, entrenamientos, recursos e información.

La pandemia dio un pequeño jiro al enfoque de nuestro trabajo, pero nuestra misión y valores como organización permanecen firmes y continuamos trabajando para crear y nutrir una comunidad amorosa e inclusiva celebrando a cada persona que experimenta una discapacidad. Como también tomando en cuenta nuestros valores, como lo importante que es que nuestra comunidad de familias tenga acceso a información actualizada, relevante, de alta calidad que sea presentada con respeto y que sea entendible para todos y así todos tengan la oportunidad de tomar decisiones informadas.

Nos hemos asociado con varios miembros comunitarios para elevar la voz y necesidades de nuestras familias Hispánicas/Latinas quienes tenemos seres queridos que experimentan una discapacidad en estos tiempos de pandemia.

Gracias a fondos que recibimos de parte de la Autoridad de Salud de Oregon, hemos podido enfocarnos en algunas barreras presentadas debido al COVID-19. Y hemos desarrollado materiales en español para aumentar el conocimiento y crear concientización sobre como luchar contra el COVID-19 en nuestra comunidad.

Son tiempos difíciles, pero no estás solo/a, para información, apoyo y recursos en español te invito a visitar nuestra página web en www.abicommunity.org/espanol/, que cuenta con recursos en español o también te puedes comunicar conmigo al 503-262-4029 o mrangel@nwdsa.org.



The Work Continues

By Maria Rangel

The last two years have been very difficult for everyone, and we have had to face different barriers, due to the pandemic. And for us at NWDSA/ABI there have also been barriers. But thanks to technology and our efforts we have been able to continue our creative support through Zoom, email, and by phone. And through these platforms we have been able to continue to provide individual supports, trainings, resources, and information.

The pandemic took a small toll on the focus of our work, but our mission and values as an organization remain strong, and we continue to work to create and nurture a loving and inclusive community celebrating each person who experiences a disability. We always recognize how important it is that our community of families have access to high quality, up-to-date and relevant information that is presented with respect, and that is understandable to all, so that everyone has the opportunity to make informed decisions.

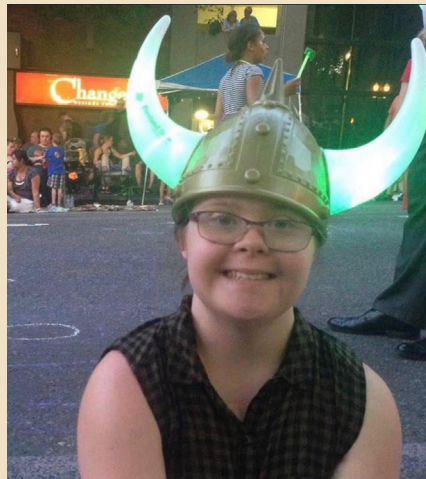
We have partnered with various community members to raise the voice and needs of our Hispanic/Latino families who have loved ones experiencing a disability in these times of pandemic.

Thanks to funding we received from the Oregon Health Authority, we have been able to focus on some barriers presented by COVID-19. And we have developed materials in Spanish to increase knowledge and create awareness about how to fight COVID-19 in our community.

These are difficult times, but you are not alone. For information, support, and resources in Spanish I invite you to visit our website at www.abicommunity.org/espanol/, which has resources in Spanish, or you can contact me at 503-262-4029 or mrangel@nwdsa.org.

A round-up on the recent successes of higher education for students with IDD

By Jamie Burch



Rachel worked at NWDSA and graduated from PSU.

Portland State University's Career and Community Studies program has now been funded for the next two years. They will be welcoming a handful of freshmen this winter who will be participating in the only inclusive four-year university option in the state.

Clackamas Community College's Oregon City campus continues to partner with West Linn Wilsonville school district's Adult Transition Program, making college accessible for their students with an intellectual disability. They hope to return to in-person classes this year.

The INVEST program at Skagit Valley College in Mount Vernon, Washington has thirty students this year, the most they've ever had. Not only do they add students each year, but they add more vocational pathways, new cohorts, and new classes!

[Continued Page 17]

A round-up on the recent successes of higher education for students with IDD cont...

The ACHIEVE program at Highline College in Kent, Washington, is celebrating successful student internships, including a film critic who showcased phenomenal writing skills for the college student newspaper and is now the 2021-22 Artistic Director for the Thunderword, and a fishing enthusiast with an extensive knowledge about bait and fish in the Pacific NW, who was offered a part-time position at Outdoor Emporium before the internship was over.

ACHIEVE is also celebrating their successful Disability Justice Week, *Disability Joy: A Mindset of Unapologetic Liberation*, a series centering the intersectionality of the disability experience through a Disability Justice framework that addresses systemic oppression and amplifies the voices of historically marginalized communities for collective liberation.

Recently, Dan Jarvis-Holland spoke to the first cohort of the Redwood SEED Scholars program at University of California, in Davis, for Disability Employment Awareness Month. He shared a presentation about jobs he has had, his education including college, what he does with the money he earns, and the best and worst parts about working. Students were excited and encouraged to think about the work they want to do someday. Redwood SEED Scholars is the first four-year inclusive residential college program in California, and self-determination and choice are planted there.

Our Think Inclusive College West Coast Coalition is working to create awareness about college for students with an IDD, and to increase options at community colleges and universities in Oregon and the NW region. Recently, we gathered community voices and sent a Coalition letter of support for PSU's Career and Community Studies program. Thank you to individuals with an IDD and everyone who reached out and participated in supporting Oregon's only university option for students with an IDD.



Writing During the Pandemic

By Mary Mullen

My daughter, Lily Mullen, is 23 years old and is a writer. I started writing like a wild woman at that age, too. I sometimes envy Lily's confidence about being a writer. She will go out for a walk with or without the dog for about half an hour, rush through the front door, slam it, grab her notebook and sit cross-legged on her bed for an hour and write. Words flow out of her onto the notebook. A solid short story about a woman runner who lives in Alaska (where I'm originally from). Or a poem full of preteen angst about feeling down and the beauty of parking her tricycle under a magnolia tree and looking up, how trees make everything better, how she is unsure about love, how the world should be kinder to people who have Down syndrome. She has a tutor who helps her learn about punctuation etc.

My first book of poetry, *Zephyr*, was published in 2010 by Salmon Poetry in Ireland (where Lily was born and where we lived until 2015 when we moved to Forest Grove, Oregon.) *Zephyr* is about my childhood in Alaska and Lily's childhood in Co. Galway, Ireland. The nights in University College Hospital were lonely and I was worried about everything, even her lack of crying: Born a few hours after the signing/of the Good Friday Peace Agreement/we lay in St. Catherine's Ward alone/ she on my stomach, leaf-weight and quiet./ While other family-shrouded babies howled/ my fingers traced her loveliness.

On sending her off to first grade I wrote First Class Trisomy 21: The moon is a big C/Hoola-hoop a perfect O/Crust of toast an L/Two plates make and 8//Life vest pressed/against tiny chest/she dives.

When Covid-19 rocked the world we found solace in our small back yard, our dog and poetry.

[Continued Page 17]

Mary Mullen's second collection of poetry will be published spring of 2022 by Hardscratch Press.



Reading 'On Tyranny' by Timothy Snyder, March 2017

By Mary Mullen

morning comes easily on 26th Ave

the short yellow bus is long gone

birds—geese or pelicans or swans

chorus over Forest Grove—too many trees

to see them but their voices are strong

Hilda's house across the street is still pale yellow

children walk to school ten bounces in front of their parents

or duckling behind

another flock sings overhead

Chase, the neighbor's rescued dog,

weeps for his people and so do I

I Call Myself Home

A Poem by Lily Mullen

I call myself home, wherever I am, I
call myself home.

I can do things that make me feel
like home.

My family is my home, and my
friends, too.

I call myself home whenever I am
doing something useful around my
house

I can persuade myself to my own
dreams of music in my lifetime,

I call myself home where I should be
in my life.

I can easily do things I like. No one
tells me.

I like my loved ones to do things with
me

Because I can do things in my own
time,

In my own ways of living, I call myself
home.

I like the feeling of being home then
I do things outside

For a long time, like playing music in
nature

And finally go back home

What can I do to love myself again...

I call myself home not always alone.

Writing During the Pandemic cont.

Lily mourned the abrupt end to her fantastic internship at Kaiser Westside Hospital through Project Search. I vacillated between fright, anger and hope. We felt lucky to have garden and fresh air. All was not always rosy; for two wordsmiths living together we used some pretty stupid words occasionally. But we also let the creativity come forth. Leaf prints, dance-chats over the fence with our little neighbor girls, writing letters to people who were doing good things, writing dreams, writing about birds at Fernhill Wetlands. I took online poetry classes from San Francisco Creative Writing Institute and Hugo House in Seattle.

The classes imposed much needed discipline on me. A Poets on the Coast workshop I had taken started a Friday submission club which gently forced me to submit my work to literary magazines. Lily's poems became songs. I was living with a singer songwriter, one that fancied herself as Taylor Swift or Ariana Grande. Music lifted us for a while but the Covid isolation mosquitoed. Lily was rescued by becoming involved with NWDSA's Self Advocacy group for young adults, and later, a music group for young adults via Zoom, and a health group, too. She got encouragement from her peers about life and her writing. Thank you to the leaders of those groups. Post-vaccinations, she got to meet her peers in person. Joy! Electronics were a blessing and a curse during Covid. Poetry was our true north. Poetry took us out of ourselves into other people's homes. I read Maggie Smith's poem Good Bones a hundred times; its punchiness kept me searching for beauty. I read women poets from Alaska and Ireland. I read tons of poems written by Ted Kooser. Oregon poets Paulann Peterson and Kim Stafford. All those chiseled and polished words were a salve to an older single mother and her sassy daughter who was just beginning to understand the concept of 'future.'

Building Collaborative Bridges for Student Success During Kindergarten Transition



Preschool and kindergarten are exciting milestones when our children move out from home and into the community. For children with disabilities, starting kindergarten isn't as simple as registering at the local school. There will be testing and Individualized Educational Program meetings, goal writing, and a placement decision deciding where your child can go to school. There are often folks at the table that you do not know, and that do not know your child. Parents should never have to feel alone and unsure during a wonderfully exciting time when their child is transitioning to kindergarten.

Our Getting Ready for Kindergarten program is presented in partnership with Multnomah Early Childhood Education Program (MECP). This opportunity provides skilled parent mentors in group and 1:1 support in Spanish and English; information about special education rights and inclusive best practices; a network of other skilled parents who have been in their shoes; training on Assistive Technology, Person Centeredness, Behavior, Visuals, Communication, and Special Education Rights, and support that meets parents where they are at.

The Kindergarten readiness program offers facilitators who have walked in your shoes and understand that parents are the experts on their children, partnering with professionals and speakers in the field of special education.

Inclusion of students with an Intellectual Developmental Disability (IDD) is a research-driven best practice. In the All Born In work over the years, we have flipped the number of students included in Kindergarten, with 9 out of 10 going into inclusive placements in contrast to national data showing that 9 out of 10 students with IDD spend 80% or more of their day in segregated settings. We know separate is not equal and we work to end segregation based on disability as part of all of our wider work.

The least restrictive environment with services and support is where everyone should start out. More restrictive environments should be reserved as a last resort after all options have been exhausted. Everyone deserves to belong and contribute and not be judged based on their disability.

We support high expectations for every child, and students should not have to earn their way into general education classrooms. Many children have already been successful in inclusive preschool settings and we know from research the value of learning alongside non-disabled peers. ABI's Angela Jarvis Holland sits on the state leadership team for High Quality Inclusion in Early Childhood. Kindergarten inclusion is a civil rights frontier that could change so much in one generation. Everyone deserves to belong and be a full part of the community.

Winter Fun!



Normally our favorite part of the holiday season is setting up a Santa meet-and-greet for all our little ones, but with the quarantine we weren't sure if it was going to be possible.

Luckily, with the support of our wonderful staff, we were able to put on a virtual Santa visit in 2020.

It brought us holiday cheer AND gave everyone a chance to ask for the right presents!



From our family to yours - Happy Holidays!

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We want to take this opportunity to introduce our new Digital Communications staff member Marcella, who has worked with multiple justice nonprofits on their website, social media, and graphic design.



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To join our mailing list and download PDFs of past issues, visit: abicomunity.org

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

Upcoming events:

On December 15th we will be holding a free holiday-themed vaccine event at Rossi Farms in Portland for **ages 5 and up**. ADA Accessible. 3:30-5:30pm.

Community drop-in support is available in English and Spanish every Thursday from 12pm- 2pm. We work to provide you tools, tips, and strategies to navigate services and provide necessary resources.

Dual Diagnosis Support Group is hosted on the first Sunday of every month. If your loved-one has a dual diagnosis of Down syndrome and Autism and you want to connect with parents experiencing the same, this group hosted by Rachel George is for you.