



Stepping Up!

NEWS FROM ABI & NWDSA
PROGRAMS OF NW DISABILITY SUPPORT

ISSUE 29
FALL 2020

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United by Love (Letter from the Executive Director) by Angela Jarvis-Holland

It's hard to believe that eight months ago, we were finalizing speaker details and lunch orders, entering your registrations into our system, and getting ready to welcome so many of you to the 2020 [All Born \(In\) Conference](#). We were also deep in the planning of a very special event, working with the [Portland Japanese Garden to bring world-class calligrapher Shoko Kanawaza to the Gardens](#), as well as to Grant High School. Shoko is a young woman from Japan who experiences Down syndrome, and we were so excited to create an event where she could speak and offer an art experience to our families.

But both events, were, like so many other things, canceled, as we entered into a season like no other. We have had so many changes to all our lives over these last several months. It's hard to capture it all in one newsletter, but we hope as you read and enjoy the photographs in these pages, you are able to get a sense of some of the joy, pride and successes we have experienced alongside the difficulties.

If I was going to sum up the last several months, it's been like moving through uncharted territory in challenging times, taking a journey without a map. But I am so proud of the way our staff and board has stepped up with resilience and flexibility to help chart a new path. Having Angela Frome, Senior Program Director, who I share strong values with and have worked alongside for 19 years, has been a great support in the seismic changes we have needed to make. Like so many other organizations, [NWDS](#) has been challenged and stretched, and we are proud of how we are meeting the changing needs of our community. We have had to navigate new technologies, distance learning, and a lot of uncertainty. Our staff, like everyone else, are managing a lot of complex demands. We are doing good work and keeping our values at the center of everything we are doing.

(Continued on page 2)



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United by Love (Continued from cover)

We know that the challenges are not equal in each family, and we bring that reality to our conversations with systems as we talk about school, early intervention, technology, health equity, and rights. We look at all of you and see so much resilience and creativity. This global pandemic is not the first challenging time in the lives of so many of our families and partners, and online learning brings a new set of equity issues. Your experiences getting through medical complications and countless advocacy struggles have helped develop muscles that are useful in this time.

So what have we been up to? Much of it is in the pages of this newsletter, from our advocacy around [distance learning](#), to the expansion of our work with the [Hispanic community](#), to the work we have been doing with the [Oregon Health Authority](#) to address new needs in the lives of our community. We continue to deepen our commitment to the black community and learn while supporting the intersections with disability. We continue to do trainings, IEP support, and one to one support, virtually and by phone.

We worked hard in collaborative advocacy to bring [Oregon Senate Bill 1606](#) into being, to ensure family members can support loved ones with disabilities during hospital stays. Whether working with the schools around equitable distance learning plans and school bonds, or doing state-level systems advocacy, we lean in to all of our wisdom and experiences and share it, with the aim of ensuring that the needs of our community are not overlooked as systems respond to this crisis. We are committed to helping shape how our families are treated, and to pushing for the visibility, respect and dignity of people with disabilities.

On a personal level, I want to acknowledge just how exhausting these times are. On the hard days, our family sometimes "loses the plot." We have taken the "get out of jail free" cards from the Monopoly game, and I have sometimes needed to pick up a card and use it! We are all doing the best we can, and we all make mistakes. Dan, like many of our kids with disabilities, brings us joy and a sense of grounding in the mix. I am so grateful for his love of simple celebrations and togetherness, for the way he will grab me for a dance as I walk to the kitchen for another cup of tea, and for moments like yesterday, when we were on a training call about [our youth work](#); in the middle of presenting he stopped to type, "I love you mom," in the chat box for everyone to see. A little sweetness goes a long way these days.

While we can't predict what the next months will bring, we know it will be a marathon, not a sprint, and we are refining the ways we sustain our work and community. Babies will keep being born, our community will continue to grow, and we will continue to be here for each other. As we head into this unique holiday season, know that we are here for you. We are stronger together, and love unites us.

Angela Jarvis-Holland, Executive Director,
NWDSA/ABI

Angela Jarvis-Holland

We cannot seek achievement for ourselves and forget about progress and prosperity for our community. Our ambitions must be broad enough to include the aspirations and needs of others, for their sakes and for our own.

~ Cesar Chavez

We would like to share our gratitude to the Oregon Health Authority, Collins Foundatin, MRG Foundation, Gary Combs, and the East Portland Eagle Lodge for their recent support of our work during the pandemic. Thank you!

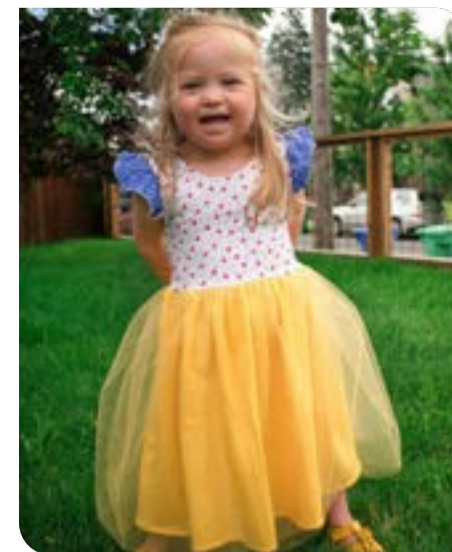
A New Sense of Normalcy

By Jonathan Cotton

When it seemed like a stay-at-home order was coming, my wife began working from home, and I transitioned my small business to our garage and basement. We were lucky to even have that flexibility, but we had a new challenge to figure out: how to occupy our 3-year-old now that her school had closed. Figuring out our new reality was like building a car as we drove it down the freeway, which is a feeling I think most people can identify with. We learned early on that structure and routine were necessary and beneficial. Not just for Lorelai, but for us as well. She was able to develop a new sense of normalcy and stability amidst a sea of changes, and we were able to create a rhythm of which one of us was "on" with our daughter, while also working.

After about six weeks, we got a much-needed lifeline. We decided to start seeing my parents, since all of us were staying home and taking the same precautions. This meant my parents could partially help with Lorelai during the week. Lorelai is a bubbling extrovert and loved getting to spend time with Grandma and Grandpa three mornings a week. We also had support from her occupational therapist, Mischa. Rather than going to Lorelai's school, Mischa met with Lorelai through video calls. They still meet weekly through video therapy sessions, which is really just playtime disguised as therapy. Lorelai knows each week when it's Mischa day and eagerly asks for their video call. Our family loves music, and we have music playing throughout the day, every day. One tool we developed early on was letting Lorelai choose the music. She's been in control of next to nothing happening to her, but she gets to have control when it comes to music selection. It's fun for her, and it's a helpful alternative when she's asking for the iPad before her screentime window.

I've also had plenty of times when I feel like I'm blowing it as a dad. I'm carrying the weight of keeping a business going and in the background she keeps asking me to play. It's usually met with, "I can't, I'm working." It reminded me of a quote from the movie Hook: "Your children love you. They want to play with you. How long do you think that lasts? We have a few special years with our children, when they're the ones that want us around." Lately I've started building time into my day where Lorelai can interrupt what I'm doing so that we can play. Nothing about this is ideal, and yet I get sad when I think about life returning to normal because this has been such a special time for our family to be together.



Tips for Teachers and Parents for Inclusive Equitable Schools During COVID

By Jamie Burch

This summer we asked families what had worked and what did not work for them and their child during remote learning in the spring. We also asked what they needed and wanted for distance learning this fall. With family input, and through consideration of best practices in inclusive schools, we created Ten Tips for General and Special Education Teachers and Parents for Inclusive, Equitable Schools, During COVID and Beyond.

1. Determine if Student Needs Food or is Homeless
2. Define Communication Details and Options to Connect
3. Determine What Technology Student Needs, and What Their Strengths Are
4. Determine What Technology Parent(s) are Familiar With
5. Decide What Type of Supports Student Needs to Engage and Learn
6. Determine What Type of Supports Parent(s) Need
7. Schedule Ongoing, Weekly Communication and Collaboration with Team Members
8. Provide Consistent and Predictable Content and Assignments
9. Plan and Schedule Routine and Interactive Instructional Opportunities
10. Post Instruction and Assignments in One Location

We are grateful to the many families and partners who continue to support this work. [Please visit our website for full details.](#)

Shout out to ALL Teachers Being Inclusive!

By Jamie Burch

About ten years ago, when my daughter was little, I remember hearing about inclusive school districts in other states that had staff dedicated to inclusion. It was the job of these Inclusion Specialists to work with students, families, and teachers to make inclusion in general education work for children with disabilities. At the time I crossed my fingers and hoped that the inclusive practices of these few school districts would cause such a big inclusive ripple effect that one day school districts everywhere would have at least one staff member who knew inclusive best practices and how to make education accessible.

While my dream of an Inclusion Specialist for every school district hasn't come true yet, over the last decade school districts that are working toward inclusion of students with disabilities are bringing on staff members specifically to support their inclusive efforts. Molalla River School District (MRSD) now has a teacher on special assignment (TOSA) to support their students and staff around inclusion. We would like to introduce Emily Knoetzel, TOSA, at MRSD, and welcome her to our inclusive learning community.

Emily gets to know students and what they need for access, and has ideas for staff to make schoolwork accessible. She is also a parent of a son with autism, and encourages other parents to advocate for Universal Design for Learning (UDL) for their children with disabilities. Like West Linn-Wilsonville, Mollala has put a stake in the ground for inclusion. The inclusive work of parents, teachers, school districts, partners, and conferences like [All Born \(In\)](#) is the ripple effect that disturbs systems of exclusion, and outwardly propels inclusion.

Working Side by Side

By Alice Miller

Hunter is our oldest, so when his little sister came around it was shocking to me that I didn't have to fight for her in the same way I do for Hunter, who has Down syndrome. Even as a small baby, his first daycare told us that he would be kept in the "baby room" rather than moving up alongside his peers of the same age, when he turned one. Because of these experiences, inclusion has been on the forefront of our minds, and at times have been quite consuming, since the day he was born. We've been very fortunate over the last few years to have support from people in our community and organizations such as Northwest Down Syndrome Association to help us prepare for kindergarten and what is to come in the public-school system.

What is interesting about this year, however, is that all the work we've put in to ensure Hunter is fully included and receiving appropriate supports has been delayed by COVID-19. We've had to change the trajectory of the last five years and get creative on the fly with what will and will not work for him. In May, we had his first IEP meeting, where it was determined he would be in the general education kindergarten class, with push-in services throughout the day, and several accommodations. All of this to ensure he is supported and can thrive in this environment. This is something I had spent a lot of time advocating for by attending the All Born (In) conference, being part of the NWDSA Kindergarten Cohort, and networking with other parents and educators who would provide invaluable advice and experiences to learn from.

Read the full article here: abicommunity/news

Is College on Your Radar for Your Loved One or Student?

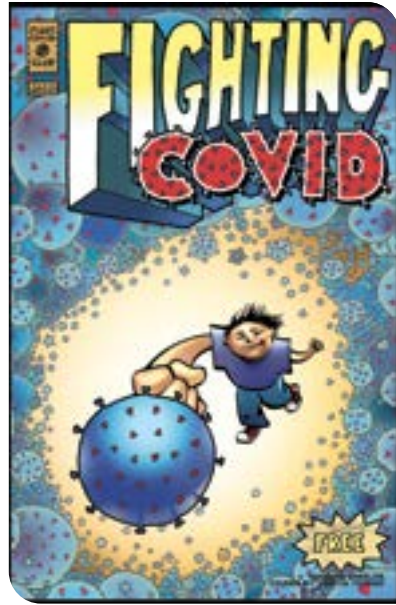
By Jamie Burch

When you think about your child's future do you think about them going to college? More than ever, college is an option for students with an intellectual disability. However, options in the western United States are limited. Until four years ago, there wasn't even one inclusive college option in Oregon.

Every four years, federal funding is awarded to expand college options for youth with intellectual disabilities. We work hard to promote more options with our Think College coalition. This funding round created some new opportunities, and Beth Foraker—who has been an active participant in our ABI summit—will be directing a new inclusive program in California, the Redwood SEED Scholars program at UC Davis MIND Institute. There will be a new program in Idaho, and Washington State has the ROAR Program. PSU and Highline are continuing their programs and commitment to our students, and we are delighted we are seeing growth on the West Coast, and more options for our youth.

Read the full article here: abicommunity/programs/think-college-inclusion-oregon-coalition





Fighting Covid, "Heck Yeah!"

By Mike Rosen

I love comics, to say the least. I've been an avid reader and collector for decades. I am a board member of NWDSA/ABI, so, when the team suggested a Covid prevention comic as a project, I said, "Heck yeah!" Or, at least, that's what I was thinking. Staff and the [youth group](#) were looking at resources, and saw a need to create a more accessible resource about fighting Covid with a person with a disability as a powerful character.

In addition to being fun, comics possess super-powers of their own. It's known that they can turn reluctant readers into ravenous ones, they give struggling readers confidence, they expand vocabulary, they can be a valuable accompaniment for other learning disciplines, and there are many different genres to suit a variety of tastes. Plus, they bring people together! When I first met Daniel Jarvis-Holland, another comics fan, we immediately had something to talk about.

Portland is "Comics Town USA," with its many publishers, artists and writers. When we decided to move ahead with this project, after securing OHA funding, I reached out to my comics artist and writer friend, [Shannon Wheeler](#). He is best known for his satirical character, Too Much Coffee Man and his New Yorker magazine cartoons. Shannon was eager to jump on board. As he said recently, "Every now and again a project comes along that's both something you believe in and is really fun to do to. This is now and I hope again. It was great."

The youth and Shannon are also looking forward to two interactive virtual sessions, where they will learn more about making comics and creating their own art. Contact Kate at kwilliamspaul@nwdsa.org for more information.

For me, it has been great working with Shannon and the NW Disability Support team, reviewing and commenting on Shannon's great work, and watching it unfold. And, very soon, you'll have the comic, "Fighting Covid," in your hands, available in both English and Spanish. The youth and families did a photoshoot with our friend Jeff at [Jeff Day Photography](#), capturing ways to be superheroes and be safe.



LOOK FOR MORE INFO ABOUT "FIGHTING COVID" AND AN UPCOMING PPE EVENT COMING SOON!

BE OUR SUPER HERO AND DONATE

We need your help to continue to use our super powers to serve families, educators, healthcare and social service providers, and disability advocates in Oregon, Washington, and beyond. Your support affords us and the wider community this privilege in times of rapid change and uncertainty. Resilience, agility, and connection have been key to our responsiveness to the challenges of this year, and we promise to use these powers with great intention, relevance, and commitment to our values and for the greater good of our community moving into 2021.



Within our community lies great strength, knowledge, and hope. Within each of you are the greatest of our super powers: shared experiences, collaborations, and relationships. We are united in love and so thankful for year-end contributions that support our mission in pursuit of an inclusive civil society.

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THANK YOU!

WWW.NWDSA.ORG



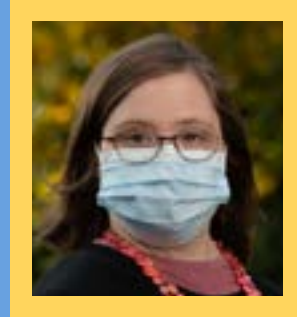
Visual Graphic from "Fighting Covid" • Coming Soon!



Gráfico visual de "Luchando Contra Covid" • ¡Próximamente!

DISABILITY & COVID-19

Know Your Rights



LAWS THAT PROHIBIT DISABILITY-BASED DISCRIMINATION IN HEALTHCARE

Prohibits hospitals from suggesting treatment is conditioned, conditioning admission or treatment of patient with POLST or advance directive, discrimination relating to administration, withholding, or withdrawing of life-sustaining procedures, nutrition and hydration.

SB 1606

OREGON



Hospitals must allow patients with disabilities to designate at least three support persons, and have one support person who is present at all times in the emergency department and hospital.

[OLIS.OREGONLEGISLATURE.GOV/LIZ/2020S1/DOWNLOADS/MEASUREDOCUMENT/SB1606/ENROLLED](https://olis.oregonlegislature.gov/LIZ/2020S1/DOWNLOADS/MEASUREDOCUMENT/SB1606/ENROLLED)



ACA FEDERAL

Section 1557 of Affordable Care Act prohibits disability discrimination in health care by entities receiving federal financial assistance.

Americans with Disabilities Act prohibits disability discrimination in public services including healthcare services offered by hospitals (Title II) and by places of public accommodation including private physician's offices and hospitals (Title III).

ADA FEDERAL



504 FEDERAL

Section 504 of the Rehabilitation Act prohibits disability discrimination by entities receiving federal funding.

CLAIM YOUR RIGHT TO HEALTH AND HEALTHCARE EQUITY

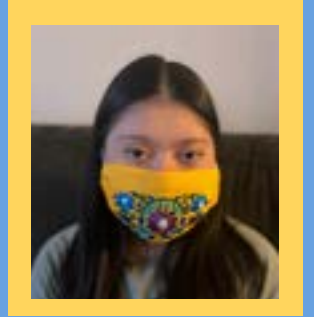
www.nwdsa.org



www.abicomunity.org

DISCAPACIDAD Y COVID-19

Conoce Tus Derechos



LEYES QUE PROHÍBEN LA DISCRIMINACIÓN POR DISCAPACIDAD EN LA ATENCIÓN MÉDICA

Prohíbe a los hospitales sugerir que el tratamiento sea condicional, la admisión o tratamiento condicional de pacientes con POLST o directiva anticipada, discriminación relacionada con la administración, retención o retiro de procedimientos de soporte vital o nutrición e hidratación.

SB 1606

OREGON



Los hospitales deben permitir que los pacientes con discapacidades designen a tres personas de apoyo y permitir que una persona de apoyo esté presente en todo momento en el departamento de emergencias y durante la estadía en el hospital.

[OLIS.OREGONLEGISLATURE.GOV/LIZ/2020S1/DOWNLOADS/MEASUREDOCUMENT/SB1606/ENROLLED](https://olis.oregonlegislature.gov/LIZ/2020S1/DOWNLOADS/MEASUREDOCUMENT/SB1606/ENROLLED)

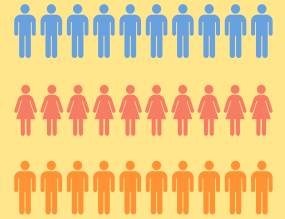


ACA FEDERAL

La sección 1557 de Cuidado de Salud a Bajo Precio (ACA) prohíbe la discriminación por discapacidad en el cuidado de la salud por parte de entidades que reciben asistencia financiera federal.

La Ley de Estadounidenses con Discapacidades (ADA) prohíbe la discriminación por discapacidad en los servicios públicos, incluidos los servicios de atención médica que ofrecen los hospitales (Título II) y los lugares de alojamiento público, incluidos los consultorios médicos y los hospitales privados (Título III).

ADA FEDERAL



504 FEDERAL

La Sección 504 de la Ley de Rehabilitación prohíbe la discriminación por discapacidad por parte de entidades que reciben fondos federales.

RECLAME SU DERECHO A LA SALUD Y LA EQUIDAD EN LA ATENCIÓN MÉDICA

www.nwdsa.org



www.abicomunity.org

¿Por qué usamos una mascarilla?

Por Maria Rangel

Estamos muy contentos de poder compartir con ustedes uno de nuestros más recientes proyectos que realizamos con mucho esfuerzo, en colaboración con otros líderes comunitarios que al igual que nuestra organización trabajan muy duro para brindar apoyo, información y abogacía a nuestra comunidad Hispana/Latina que experimenta discapacidades intelectuales/desarrollo y con el patrocinio a través de fondos que nos fueron otorgados de la Autoridad de Salud de Oregón (OHA).

El proyecto consiste en la formación de un video de la importancia de que todos usemos una mascarilla.

El video fue realizado esperando traer concientización de la importancia de usar una mascarilla no solo para protegernos a nosotros mismos sino, también pensar en proteger a todos en nuestra comunidad. Ya que, aunque el Covid-19 no presente una amenaza grave para algunos, hay personas dentro de nuestra comunidad que están a mayor riesgo de que Covid-19 sea fatal para ellos, por ejemplo, para nuestra comunidad con sistemas inmunes más comprometidos como es el caso de muchos quienes experimentan una discapacidad.

Los invitamos a compartir este video con sus familiares, amigos, vecinos y por todas partes para así compartir el mensaje de la importancia de protegernos y a la vez proteger a nuestra comunidad más vulnerable.

Para ver el video, pueden entrar a nuestras páginas de Facebook, Asociación de Síndrome de Down del Noroeste (en Español) o Northwest Down Syndrome Association (NWDSA) (en Ingles) para mirar el video y compartirlo o también pueden ir directamente a nuestra página web https://www.abicomunity.org/espanol/recursos_en_espanol.html y encontrarlo bajo la sección de Recursos COVID-19 bajo el título ¿Por qué usamos una mascarilla? Y también encontraran más recursos e información que hemos recolectado en español sobre el COVID-19 y más.



MARIA RANGEL, COORDINADORA BILINGÜE DE LOS PROGRAMAS NWDSA/ABI

Debido a la pandemia por ahora nuestros apoyos son vía telefónica o virtual a través de video llamadas. Todos los jueves de 12pm – 2pm tenemos horas abiertas para apoyo comunitario en español vía zoom donde podemos apoyarle en temas como la educación especial, ofrecemos entrenamientos en español por la plataforma de Zoom, y para nuestros entrenamientos vía Zoom, que son en Ingles ofrecemos interpretación en vivo.

Para más información, recursos, o apoyo en español pueden contactarme dejándome un mensaje al 503-262-4029 yo les regreso su llamada tan pronto me sea posible, o también me pueden escribir un correo electrónico a mrangel@nwdsa.org.

Contact Maria Rangel, Bilingual Outreach Coordinator,
at 503-262-4029 or mrangel@nwdsa.org
for more information, resources, or support in Spanish.

Encuentra más información en español aquí: www.abicomunity.org/espanol/.

El poder de las voces de las familias

Por Maria Rangel

La abogacía no siempre genera cambios de la noche a la mañana, pero el poder de las voces y necesidades de las familias conectadas de manera organizada es poderoso.

Una madre llegó a NWDSA / ABI con necesidades urgentes para su hijo y trabajó junto a Maria Rangel, nuestra Coordinadora de alcance comunitario bilingüe. Pudimos ayudarla a abogar por esas necesidades para que se solucionarán en PPS, también descubrimos las necesidades de un grupo más amplio para la comunidad Hispana/Latina en general que tiene hijos e hijas que reciben servicios de IEP.

Trabajando juntos, ayudamos a fortalecer sus voces y con el duro trabajo de la comunidad y la atención de PPS pudimos abogar y elevar la importancia de la necesidad de una coordinadora bilingüe que pudiera ayudar a apoyar a las familias Hispanas / Latinas a navegar la educación especial.

Hoy con gusto le damos la bienvenida a Paulina Larenas, quien trabajará junto con Noelle Sisk, Coordinadora de familia y la comunidad de educación especial de PPS y defensora del éxito estudiantil como la primera coordinadora bilingüe de familia y la comunidad de educación especial de PPS y la defensora del éxito estudiantil.

Esto requirió valor para que las familias hablaran y estamos agradecidos de que Guadalupe Guerrero, superintendente, de escuelas públicas de Portland (PPS), la junta escolar y otros líderes escucharon y dieron un paso al frente. Esperamos colaborar para satisfacer las necesidades de más familias con la ayuda de esta nueva posición.



The Power of Family Voices

By Maria Rangel

Advocacy does not always create change overnight, but the power of family's voices and needs connected in an organized way is powerful.

A parent came to NWDSA/ABI with urgent needs for her individual child, and worked alongside Maria Rangel, our Bilingual Community Outreach Coordinator. We were able to help her advocate for those needs to be met at PPS, and we also uncovered wider group needs for the wider Hispanic/Latino community who have children on IEP's.

Working together, we helped strengthen their voices, and with the hard work of the community and PPS listening, we were able to advocate and raise the importance of the need for a bilingual coordinator that could help support Hispanic/Latino families navigating special education.

Today we warmly welcome Paulina Larenas, who will be working alongside Noelle Sisk, PPS Special Education Family and Community Coordinator & Student Success Advocate, as the first bilingual PPS Special Education Family and Community Coordinator and Student Success Advocate.

It took courage for families to speak up, and we are grateful that Guadalupe Guerrero, PPS Superintendent, the PPS School Board, and other leadership listened and stepped up. We look forward to collaborating to meet more families' needs with the help of this new position.

The Best Work is Done When We Strive to Be Kind and Brave

By Kate Williams-Paul

Hello! My name is Kate Williams-Paul, and I am very excited to join the team as the Youth Outreach Coordinator. I grew up active in the disability community in my hometown with my cousin Lauren. She and other friends who experience disabilities inspired a passion for disability justice and activism. After graduation, with a BS in Psychology and a certificate in Applied Behavior Analysis, I offered structured skills support to children and teenagers experiencing intellectual and developmental disabilities. This group challenged every lesson and piece of advice I'd been offered about how to "teach" young folks with disabilities. It opened my eyes to a lack of diverse, comprehensive resources the young folks I worked with desired, like dating and sexual health education, health and wellness resources, tools for self-advocacy, and ways to explore jobs related to their individual passions. Two years ago I returned to work with teens and young adults, with a specific focus on equitable and inclusive health and wellness, intersectional social justice, and striving to listen to and amplify the voices of the young people in my world.

My work is fueled by the ideas that to achieve collective freedom and liberation, everyone in a community should be viewed as both a learner and a teacher. Joining this team feels like such a wonderful opportunity to continue to learn and grow these values. I am inspired by this team to challenge systems, ask questions, work hard, and make meaningful changes. The first project I collaborated on as part of this team was the Yes to PPS! Bond Measure video [[Disability Rights are Civil Rights; Vote Yes on PPS Bond, Measure 26-215!](#)] This project was headed by Arly Holzweissig, an advocate for disability justice, and high school student! It was so incredible to participate in a project that was directed by a teenager passionate about inclusion and change.

I will help co-facilitate the [Social Justice Youth Program](#) alongside Will Larson and Rachel Esteve. As Will says, our team is so powerful because "Everyone advocates for everyone." There is no right or wrong way to contribute. We all have a voice. That passion and energy contributed to many creative projects this fall: a Covid comic, a superhero-themed photoshoot, powerful conversations about voting, rights, and disability pride and justice... and many laughter-filled meetings of our Social Justice Youth Group.

I believe that the best work is done when we strive to be kind and to be brave, to ask questions of the young people in our worlds and listen carefully and thoughtfully to their answers. I am inspired by Lilly Mullen, a powerful self-advocate in the Social Justice Youth Group who challenges us to:

"Imagine a world where we all count. Voting is a public way of saying our families count and our voices matter. Count us all in... Don't forget us! We are everything in a world who supports us".



JOIN OUR SOCIAL JUSTICE YOUTH COMMUNITY!

Are you or a young person in your life interested in joining our group of young adults with and without disabilities to work towards a shared dream of an inclusive, brave, and kind future where EVERYONE has a space at the table in our community?

Reach out to me (Kate) at kwilliamspaul@nwdsa.org!

Follow us on social media, too, for videos, activism, and an upcoming blog collaboration with AUCD and our Social Justice Youth Group. The future is accessible!

📍 [facebook.com/socialjusticeyouthPDX](https://www.facebook.com/socialjusticeyouthPDX) 📷 <https://www.instagram.com/youth4socialjustice>

The Power of Planning

By Larry Deal, Independence Northwest Brokerage



"It does not do to leave a live dragon out of your calculations, if you live near (one)," wrote J.R.R. Tolkein.

While 2020 hasn't threatened us with dragons (yet), Tolkein's quote certainly resonates: know the risks around you and when you can, make a plan. This year has brought Oregonians plenty to contend with: a pandemic, historic windstorms and wildfires, serious air quality concerns, and flash floods. Some situations we could have planned for, others required in-the-moment creativity and a willingness to roll with the changes.

This spring, many families (my own included) faced major challenges when a loved one was admitted to the hospital and we were told that, due to COVID-19, visitors weren't allowed inside as a support. This left families across the country scrambling to figure out what to do in an unprecedented situation. Disability advocates and Oregon policymakers worked swiftly to craft a bill that would afford Oregonians the right to have a support person by their side when hospitalized, even during a pandemic. The result was the passage of Senate Bill 1606 in July. Nothing is more essential than being able to communicate one's needs in the midst of a crisis – and this essential piece of legislation has secured us a right we didn't have just a few short months ago.

In the week following Labor Day, communities throughout our area experienced unprecedented winds and wildfires. At Independence Northwest brokerage, we serve about 500 Oregonians with disabilities, and at one point, one-third of those we serve were in evacuation zones. The fires in Clackamas County moved swiftly and on countless occasions, calls from our agency marked the first time many people we serve were notified that they were under evacuation orders. Some families had to-go bags and plans in place; others had to create immediate plans to pack up and leave the area. Some knew where they would go, others had to rethink everything because other friends and family were under evacuation orders as well. The rapid nature of the event underscored one truth: even the best-laid plans can change.

It's tempting to put off planning. Given just how challenging the year has already been, it may even be hard to find motivation right now. Sometimes it's hard to even know how to get the conversation started. We've pulled together a list of resources for you to check out to help you start (or re-visit) conversations with those you love. Plans don't have to be perfect – and sometimes just having a conversation can make all the difference.

Visit www.independencenw.org to learn more.

They Will Be Just Fine

By Leah Thompson

As my family prepared to begin distance learning with my two young children, a 4th grader with Down syndrome and a typically developing first grader, I was unbelievably worried and stressed. I couldn't imagine how I could support both my kids with school and also fulfill my job duties working from home. These days everyone feels like they're doing both too much and not enough at the same time, and I am no different. But my most acute worry was how my daughter who experiences disability was going to fare. I worried that the new distance learning schedule, with its increased focus on virtual classroom meetings, was going to be inaccessible for her, and that she would start to pull further and further away from her peers in her general education classroom. We have always insisted on inclusion and she has been alongside the same kids since kindergarten. Even though she relies on supports, modifications, and even some select pull-outs, she has always loved school, and she has continued to learn and make progress.

So my worries of making the new normal available to her loomed pretty big. Who would modify the material? How would she get support from her paraprofessional, her special ed teacher and her speech and occupational therapists? How would she fare with so many online meetings, especially when I know she struggles attending to computer screens and benefits so much from peer modeling? Would I have to sit next to her the entire school day, missing work and not being available to my first grader? So I jotted down a long list of suggestions, and we met remotely with her IEP team a week or two after school began.

Some of the supports that seem to help are a desk space that is screened off from the rest of the room, a touchscreen Chromebook, captioning turned on during her classroom meets, breakout rooms with her para at the end of her meets to allow for questions and check her understanding, a dry erase board, handwriting paper to help her write, a typing app so she can practice her typing skills, additional ways to turn in assignments (verbal responses, shorter answers, sometimes transcribed by myself or her para, sometimes written by hand, and sometimes typed), paper worksheets in addition to online tools, and extra breaks for movement. Initially the schedule of online meetings was overwhelming, and she longed for time to work independently, so we reduced her specialist meetings. It is true that I am still providing a lot of assistance. I try to listen in to at least half of her meetings so I can support her with assignments and I do end up modifying quite a bit of her work. I spend way too much time reminding both kids to pay attention. I wake up super early to squeeze a few hours of my own work in before their school day begins. I get creative with arranging the kids' schedule so they can have extra breaks and do asynchronous learning together. But honestly, one of the biggest things we've done that has helped is to let go of the idea that we have to get every single assignment and meeting done and done well. Sometimes it feels like too much and we all get burnt out, so we let some things go and give ourselves some grace. I am grateful to have flexibility with my work, access to the tools we need, and a supportive co-parent who oversees school a couple days a week.

And while I know it is far from perfect, I have been surprised at how well she is doing. At the end of the day, my daughter still loves school, even through distance learning. She longs for the day she can go back in person, and she misses her friends and teachers fiercely. But I'm also surprised at the camaraderie I still see in the online interactions with her peers. I am loving the extra insight I get into both my kids' strengths and challenges and what they are learning. Even though I know the kids are losing a lot of opportunities, I am happy to see the connections they are still managing to find. I am so impressed with the efforts of their teachers, who are working so hard to make this work. And I am very proud of the resilience of my children. While I can't wait for it to be safe enough for all our children to be back in school, I am happy they are home and safe. And overall I know they will be just fine.



THANK YOU FOR PARTICIPATING IN THE 22ND ANNUAL #BUDDYFESTNW!

Message of gratitude

On Saturday, August 29th, we held the [22nd Annual #BuddyFestNW](#) and our first ever online celebration of our lives with [Down syndrome](#). While we were most certainly concerned with how our largest celebration and fundraiser would translate in the virtual world, we found the spirit of community held strong, and we are thankful for all those who came together to remind us what #BuddyFestNW means to them and that we are most certainly better together!

Thank you to all our participants, donors, and special contributors including [Karen Gaffney](#), [Emmie Blue and the Squatchie](#), [Jonas Hartley and his Magical Creatures](#), and [Wallace](#) featuring Newell Briggs! Huge thanks to the beloved [Tony Starlight](#) for opening up the Tony Starlight showroom to make this day possible. We are happy to report that together we fundraised over \$20,000 to support our work valuing relationships, social justice, equity, diversity, and self-determination!

SPECIAL THANKS TO OUR TOP TEAMS, INDIVIDUAL FUNDRAISERS, AND DONORS!

- 1) The Bullwinkles
- 2) Team Ivy
- 3) Archer's Team
- 4) Team Frome It Up!
- 5) Karley's Krew

- 1) Eric Cerdena
- 2) Mary Hatcher-Heerling
- 3) Allen Scobba
- 4) Sylvia Cerdena
- 5) Kristian Burch

Campbell Global, Capitol Electric Co., Richard Downie at State Farm, Britton Frome, MB Law Group, Capitol Data & Communications, and MESD AFSCME Local 1995!



Staying in Between Fear and Gratitude

A dialogue between Adara Morgan, Abby Braithwaite, and Neera Malhotra

Neera: I am so happy that we three get to discuss this precious topic. It is great to be with both of you. I still remember when we met for the first time, Adara, you were around four years old- wow time flies too fast! I remember meeting at your home and also at the ABI conference several times. This is fantastic—I am looking forward to this conversation. We will be interviewing each other, right?

Adara: Yeah, that's right!

Abby: There's no question the past seven months have been some of the most challenging and surprising for all of us around the globe, between the pandemic, politics, and unrest. But there have also been some bright spots for our family. Living through this time as mom has given me the privilege of seeing through the eyes and hearts of my children. Adara, you have helped me in so many ways to live through this time. Can you tell Neera what your life has been like since March?

Adara: I have to homeschool here with my mom, and do my work here instead of going to school. I like the work here, but I miss Cascadia. I also miss my old school before Cascadia, with the cafeteria, and PE, and all the people.

I lost my friends, and lots of places are closed—OMSI, Skyzone, Chipotle. I have lots of mixed-up feelings—sad, angry, frustrated, nervous. We went to the beach and I was shy and afraid of strangers.

I love playing with my brother because I see him more than before Coronavirus. We have fun together, but we butt heads a lot. Neera, it is nice to see you? How are you?

Neera: I am happy to be talking to you both. I am hurting, in pain, and tired most of the time. I am also grateful for love, friends, and family connections. That keeps me going. I am paying attention to what my body is feeling. How is it for you, Adara?

Adara: Sometimes my body has to cry. Sometimes I feel anger and sadness in my throat but I find calmness in my belly and take a deep breath. I learned that doing Cosmic Kids Yoga, with Zen Den. Zen Den talks about how you feel, the things you miss, and teaches mindful walking. The teacher is Jamie. She is a good, good person. She helps me do yoga with fun stories like Harry Potter.

Abby: It's so easy for me to get lost in the stress of the moment, and to become overwhelmed by all I have to do, and all the hard things that are happening in the world. Adara, every day, you help bring me back the here and now, and help me feel all my emotions. You are so in touch with how you feel and you allow yourself to be sad or mad or full of joy when you need to. We have had many nights of bedtime tears, with you remembering all the people and places you miss, but you wake up every morning hoping that Coronavirus is finally "over" and life can get back to sleepovers and outings.

Neera: We live in such uncertain times, and the heightened social, political, and environmental crises this year have touched and awakened our minds. We are more present and aware of fear, distrust, and discomfort. Everything seems urgent and we find ourselves being at the edge all the time. It seems to me that Mother Nature is bringing to us the wisdom of being "in-between," being in the center—accepting and honoring the not

knowing. I see that there is wisdom hidden in fear, distrust, and discomfort. We need to listen to that. What helps you, Adara?

Adara: Deep breaths. Calm talking. I like to swing and listen to music and sing. Sometimes my parents don't let me, and that makes me kind of sad. I try to do my chores and my responsibilities so I can have my music when I need it.

Sometimes I am happy because I have more time with my family, and Liana and Anna. I love eating big dinners with my family, and watching movies. Me and my brother watch a weird, weird, weird show called Rabids.

Neera: Nice. One day at a time as I remind myself.

Abby, I also want to address how the differences in our socio-economic structures, race, and gender have impacted our ability to stay in between this sadness, fear, and joy of not knowing. I know many of my friends have left jobs as it was getting hard for them to teach their kids while working at home. But, it is important to note that they could afford to do that, whereas I also know many of my friends who were laid off and are experiencing this time very differently. I want to bring this to the forefront, too, as we look at the values of gratitude and breath practices.

Not everyone can breathe and not everyone is able to come to the center as individual experiences are different. But, our individual experiences are guiding us moment by moment and shaping our resilient self. We all hold those tools within our existence. It is important to honor and listen to what the body is saying- grieving- and crying. That is where the hidden joy is located in the form of resilience and growth.

I urge us all to hold on to the practices that give us joy and a deep connection to the body and the soul. Take refuge in the gifts of deep breaths, as Adara is reminding us. Perhaps giving ourselves permission to stop when needed and go when ready—being open to the curiosity of staying in between joy and fear, happiness and anger, calmness and restlessness—it requires courage and grit. It requires tenderness and openness. Everything you have is required. Then we can be available to remind ourselves that uncertainty could be a gift and an opportunity to be creative.

I also urge us to be open to sadness, grief, and tears—they are companions, too, just as joy—tears and grief offer us essential body wisdom to let go and be calm.

I invite us all to engage in sixty to ninety seconds of doing nothing every day, remembering our ancestors and elders, and remembering the breath that is with us all the time.

Thank you, Adara and Abby, for your wise presence and love.





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Community Drop-In Support
Every Thursday from 12pm-2pm
English & Spanish
Resourcefulness Center
11611 NE Ainsworth Cir, Ste 321 • Portland, OR 97220
(503) 238-0522 • abicomunity.org • nwdsa.org
Para comunicarse en español,
llame a Maria Rangel (503) 262-4029



WE LOOK FORWARD TO SEEING YOU!
Check out our event calendar for more details
about this year's Winter Social and to register!

We will continue to add free virtual events to our calendar. Keep a look out for future offerings!
Every Thursday • Community Drop-In Support
December 01 • Giving Tuesday
December 02 & 16 • Guided Meditation & Healing
December 06 • Winter Social
January 13 • IEP Rights & Laws
March 21 • World Down Syndrome Day
Full calendar at abicomunity.org/events