OFF THE BEATEN PATH

Four Autistic Leaders...
Building Bolder, Better Lives
For Themselves and Others

THE VIEW FROM HERE • DREAMING AUTISTICALLY • AND MORE!
A Journey with Fire

BY BRIGID RANKOWSKI

In this issue, Brigid shares how the circus arts have changed her life and her commitment to building accessible circus arts programs for kids and adults with disabilities. This article is part of our cover series on four autistic trailblazers who are building, bolder, better lives for themselves and others.

“Spin to the right for thirty seconds and then spin to the left. Breathe deep as you spin faster and then slow down.”

Six years ago, at the urging of a friend, I nervously attended an event that would change the course of my life. WOMBAT, the Winter Object Manipulation Bootcamp At Tufts, is a juggling and spinning arts workshop that is part of the Flow Arts community – movement art that promotes a state of “flow” or completely being in the moment. I instantly was drawn into the activities; I realized that I had discovered a passion and there were supportive people who could teach me anything my heart desired. I was encouraged to go to another event later that month called Wildfire. At Wildfire, I found well known, talented performers sharing their skills with large groups of students eager to learn new tricks and I also found people knowledgeable about a subject I hadn’t ever been actively exposed to growing up: fire itself.

Being the rule-bound person I am, I was very curious about the science of fire and how we can perform with fire in the safest way possible.

The first prop I ever used was a staff, which functions almost identically to the bo staff I had long ago used in martial arts. Five years later, I now perform with 9 different fire tools and continue to strive for individual improvement with each one. The reason I perform with so many different types of props is actually directly related to my disabilities. As well as being autistic, I have Ehlers-Danlos which is a connective tissue disorder. By spinning the same prop in the same way for hours to practice, it was starting to cause me trouble with my grip strength and muscles. By using new props all the time, I began to improve without wearing myself down. I found by spinning, I was getting better at the skills but more importantly I was relaxing myself. The act of spinning in a circular way was forcing my body to relax and causing my body to regulate its breathing. Whenever I was stressed, I was able to spin to calm myself. This intrigued me and I quickly found out there were many other people in the Flow Arts communities who used their props to help calm themselves and reduce anxiety.

My interest in the movement arts quickly expanded
and, in the summer of 2016, I produced my first professional stage production called The Way We Move as part of the Portland, Maine branch of the International Fringe Festival. The show was about how there are some things, secrets or emotions, we can’t put into words but we can express them through movement. The show was connected to disabilities by including other performers with disabilities and placing an emphasis on non-verbal communication as a valid form of communication. After the production wrapped, I combined the idea for the show with a project I dreamed up for my Master’s thesis. I wanted to create accessible flow arts programs to promote creativity, confidence, and skill development in the disability community.

In the winter of 2016, I received a grant from Fund the Flow Arts to produce The Way We Move as a 6 week long flow arts and circus camp for children and adults with disabilities. I rented space at Circus Maine in the winter of 2017 and had each week taught by different performers who also had experience working with the disability community while I provide support to the participants. It was very successful and we are working to continue using that as a program model, but expanding it based on the needs and interests of participants. In 2017, we ran programs for six of the twelve months of the year with notable partnership support from Congress Square Arts, Portland Museum of Art, and Maine Goes Gold for Childhood Cancer.

With the clear need for circus arts in the disability community, The Way We Move has already grown so much more in 2018. We are actively working on filing to be a federally recognized 501c3 non-profit with the support of a wonderful board. In Portland, we continue to offer monthly free circus programs in the summer and we have also brought the accessible circus arts to Pride Portland. Once we get our official status, we will be working on a benefit event and applying for grants to secure funding to resume offering weekly accessible circus programs to start in the winter of 2019.

“I know now more than ever my future involves building accessible circus arts programs for kids and adults with disabilities. My life is better for having Flow and Circus arts in my life, so I will work to allow others the life-changing experiences.”

Currently, I’m an insured fire performer licensed in both New York City and the state of New Hampshire. I act as the main organizer for the Maine Fire Dancing Collective, which was the winner of Portland Phoenix Best Street/Performance Artist 2018 award. My other main commitment is as the Fire Producer at Harry Brown’s Farm running their fire troupe the Fire Benders. I perform professionally as Brigid Sinclair across New England by myself and with others. During the school year, I run an after-school program teaching kids circus and flow arts.

The circus arts have welcomed me with open arms as I actively discuss accessibility and disability intersectionality in the growing field of social circus, which involves working more on the intrinsic benefits of circus such as confidence or balance instead of only promoting mastery of skills. This past spring I had the opportunity to train with Cirque Du Soleil’s social circus program and felt I had really found my place working to develop The Way We Move. With a car accident at the end of May this year, I know now more than ever my future involves building accessible circus arts programs for kids and adults with disabilities. My life is better for having Flow and Circus arts in my life, so I will work to allow others the life-changing experiences.

When I spin fire or when I am in the “flow”, I am able to be, well, me. I use my autism to run spinning events with an emphasis on safety and promoting community by being able to effectively communicate about what is very much my special interest. Both the Flow Arts and Social Circus are growing fields and this gives me the chance to immerse myself in learning the newest techniques while they are actively being created. I have forged my path literally in fire and I’m so proud to help other people find their creative passions in this field.

Brigid Rankowski is a Portland, Maine based advocate and performer who works with both state and national disability organizations to promote more intersectional resources for those in the Autism community. She currently speaks on women’s issues, healthcare access, internet safety, creative art programs, trauma, employment, and lgbtq+ inclusion. In her free time, she enjoys breathing fire. Follow her on Facebook.

Flow arts photos by Jake Wisdom; Bio image by Sean Hayes Photography
In this issue, Finn talks about making life fairer for all through his disability advocacy and activism. This article is part of our cover series on four autistic trailblazers who are building, bolder, better lives for themselves and others.

The gap between the ideal and the real is, and always has been, the impetus for my involvement in advocacy, even if I didn’t always describe it that way. From a young age, I have experienced the discontinuity between what is and what ought to be in a profound way, and found it difficult to accept answers like “that’s the way it is” and “life’s not fair” from the adults around me who seemed oddly acquiescent towards systemic injustice and unfairness. Life may not be fair, but I felt a need to make it fairer. I was shamed, though, for wanting to set the world to rights. When I was 14, my parents thought I was going too far when I tried to tell them about the squalid working conditions in Chinese factories. Something similar happened three years earlier, when I tried to warn my mother about the mistreatment of garment workers in Latin America and South Asia after having read articles in *Time Magazine* about workers’ rights.

“It was the autistic self that was unacceptable to my family; no matter what I did, they would turn it into something that had to be fixed for the sake of appearances.”

For my parents and many of the other adults around me, my concern for the state of the world was framed in the language of pathology; my idealism was an aspect of my being autistic that deserved ridicule and dismissal. They were turned into contextless “obsessions,” detached entirely from any considered ethical stances that I might have held. Paradoxically, if I had been totally uninterested in other people, it would have been treated as a trait of the same condition, given that autistic people are routinely thought to lack empathy. What I said and believed could be dismissed because it came from someone who was considered intrinsically “disordered,” *even if those beliefs reflected consideration for other human beings’ wellbeing*. It was the autistic self that was unacceptable to my family; no matter what I did, they would turn it into something that had to be fixed for the sake of appearances.

I believe that my ability to notice the difference between what was and what could be is connected to the ways in which I have been pushed to the margins of society; being queer, black, and disabled in a society that wasn’t created for me has made me acutely aware of this yawning gap. I weave intersectional principles throughout my disability advocacy and activism because of my lived experience. Autism, and disability in general, do not exist apart from a wider social context. Race, gender, social class, immigration status, sexuality, culture, and other experiences affect the ways that autism is both experienced and perceived. For example, Simon Baron-Cohen claims that autistic people have less empathy than non-autistic people. Crossing this with the idea that black people also have less empathy can result in dangerous consequences that may ultimately be fatal. Disabled people are more likely to experience police violence because we are often seen as creatures who are only part-human, if that. A similar phenomenon occurs with racial stereotyping.

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Feeling more comfortable with my identity as an activist and moving past the shame entailed accepting myself in all my complexity, rather than seeing myself as a list of pathological traits or disconnected interests. I had to be able to see myself as a full human being before I could fight for my own human rights. Of course, this shift wasn’t about repudiating an autistic identity; it was about understanding that my being autistic was not synonymous with my being broken. In my late teens and early twenties, I started reading articles about neurodiversity and the social model of disability and spent time in autistic advocacy circles online. Writers like Mel Baggs and Jim Sinclair both...
reminded me that it was all right to exist in the world as autistic and that there was room for me to advocate for the rights of autistic people and other people with disabilities. I could bring the ideal and the real closer to each other without feeling guilty for even noticing that there was a difference between the two.

“**It's absolutely OK to be autistic and to have strong values that you hold dear. You deserve to exist just as you are.**”

By the time I was in my mid- to late twenties, I felt sufficiently comfortable with my autistic self to get involved with more public advocacy, like writing an op-ed against an Autism Speaks fundraiser for my student newspaper, joining my local chapter of the Autistic Self Advocacy Network (ASAN), attending ASAN’s Autism Campus Inclusion (ACI) training, and giving a talk to a class about ableism. It sort of became an avalanche after that; a few years after attending ACI, I started

- working with ASAN as a remote staff member collaborating with a team of researchers on gauging attitudes towards the creation of an autism database in Massachusetts, staffing ACI trainings, and writing policy briefs and reports on issues affecting autistic people and other people with disabilities;

- conducting presentations and participating in panel discussions about intersectional disability rights in a wide variety of venues, including the United Nations, MIT, the Ruderman Inclusion Summit, the American Association on Intellectual and Developmental Disabilities, and the White House during the Obama administration;

- and working on a master’s degree in public policy at the Heller School for Social Policy and Management, which I completed this past May.

I'm glad that I chose to let the shame go and jettison the idea that I had to suppress my ideals to be “healthy.” I don't think I would be where I am now if I didn't stick to my ideals and work actively to make social inclusion for people with disabilities a reality. It's absolutely OK to be autistic and to have strong values that you hold dear. You deserve to exist just as you are. In these turbulent times, we need more people to stand up and fight for inclusion, justice, and equality. We can't sit around waiting for our heroes to come and fight for us; we have to be our own heroes.

Let’s work together to create a kinder, more inclusive world in which to live.

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**Finn Gardiner** is a Tufts University graduate in Boston who concentrated in Sociology, and a community activist who has worked with various groups, primarily regarding LGBT rights and disability advocacy. He brings his experience and passion for fusing creativity with social justice at **ASAN** as the Boston Community Coordinator.

**What Can Neurodiversity Libraries Do for the Autism Community?**

**BY LEI WILEY-MYDSKE**

In this issue, Lei writes about creating the first autism lending library that is focused on the ideals of neurodiversity and autism acceptance. Now she is helping others do the same in their communities. This article is part of our cover series on four autistic trailblazers who are building, bolder, better lives for themselves and others.

It is fairly easy to find information about autism if you look. What is harder to do is to find information that is accurate, respectful, helpful and that centers the voices and experiences of autistic people. It is rarer still to find information that considers the ideas of neurodiversity, autistic pride and autistic culture. As an autistic adult and parent of an autistic person, and someone who is a really huge fan of autistic people in general, it's important to me that our voices are not just tolerated but prioritized and celebrated.

In 2013, my son and I were at our local library and
on a whim I decided to see what books they had available on autism to the people in my community. Of the three books that were on the shelves, all were in the parenting section. One was written by a non-autistic parent. One was written by a non-autistic professional and just one was written by an autistic person. All of the books were written for parents specifically and contained information about helping them to cope with an autism diagnosis that in my opinion, was both toxic and ableist. There was nothing about how to support and accommodate their children that considered their rights or dignity. None of them promoted a loving relationship between parent and child, but instead gave tips on managing and manipulating their children into compliance with neurotypical social norms. There was nothing that spoke to the invaluable expertise that autistic people themselves offered. The idea of celebrating autistic people as a valuable part of human diversity was unheard of. None of the information in these books reflected our reality or addressed our needs.

“All of the books were written for parents specifically and contained information about helping them to cope with an autism diagnosis that in my opinion, was both toxic and ableist.”

There are books and resources out there that do get it right, but they are often overlooked and ignored in the mainstream discourse surrounding autism. I knew that the right resources were there, but just not as widely available to people who might not know how to find them. There were so many better ways to educate people about autism, disability and neurodivergence. I knew that autistic people, adults and children alike needed access to resources that told them that who they are is not broken or a burden. I wanted autistic people to be empowered to be strong self-advocates and to know that having a disability was not negative or shameful. I wanted everyone to know that autism and disability are a natural and inevitable part of human diversity. That it is good to be proud of your neurology and to know that we all deserve to be respected and included no matter how much help or support we need, no matter how we communicate, how we move or experience the world.

Later as I thought of how disappointing the resources available in my community were, I mentioned to a friend who is also an autistic adult that I should just start our own library with materials that could actually help people. He told me that I should. Together with my son and the support of my non-autistic spouse, I created the Ed Wiley Autism Acceptance Library. It is the first autism lending library that is focused on the ideals of neurodiversity and autism acceptance.

The first thing we did was to gather books, films and resources from donations and crowdfunding. We found a space in our local community center to meet people and set up our collection a few times a month. We also decided that in order to be more flexible and accommodating, we would do appointments as well. During our first year we also held a special community event that has become an annual Autism Acceptance Month tradition where we collaborate with Autistic Women & Nonbinary Network (AWN) in April for a free film screening about acceptance in our community.

Most the books and films that we offer for lending are written by autistic or otherwise disabled people. We try to showcase books and materials that are most reflective of the neurodiversity paradigm and that advance the cause of autism acceptance and the rights and dignity of disabled people. Many people are surprised that we also offer poetry, fiction and art by autistic authors and creators as well as information on autism. We also have a big focus on inclusive education and inclusive communities, so we have lots of resources to help people know their rights and to understand what real inclusion actually means.

“I wanted autistic people to be empowered to be strong self-advocates and to know that having a disability was not negative or shameful. I wanted everyone to know that autism and disability are a natural and inevitable part of human diversity.”

We have also developed our own resources on autism acceptance with the neurodivergent narwhals. These are short infographics and posters that seek to break down more complex ideas so that they are accessible and easier to understand. As a hyperlexic, I often have trouble processing information as fast as I can read it. This makes reading an entire book somewhat difficult for me. I read things multiple times in order to fully understand and I wanted to find a way to help people who may have similar issues with reading or who may just not have the time or patience to read an academic essay or book on the neurodiversity paradigm. Accessibility is more than just being able to easily navigate a space, so it is very important to me that the library is not just about books but about sharing ideas and creating access to information.

“We have also developed our own resources on autism acceptance with the neurodivergent narwhals.”
Several months after we started the library, I was contacted by Lana Thomas, who wanted to start a similar library in her community. She founded Unbound Books Autism Acceptance Library. Soon, others from across the United States and around the world contacted us as well about starting a library and challenging the negative messages about autism in their communities with acceptance and by embracing neurodiversity. We now have numerous grassroots community lending libraries that are working together to exchange ideas, resources and information to create a better world for autistic people. Some are mail order, some are set up as Little Free Libraries, some collect books to then donate to their local public library, local schools and disability organizations. There are so many ways to run a neurodiversity library. It really depends on what is most accessible to you, the time you can devote to it, the needs of your community and the money/donations that you are able to raise.

My son and I started our library partly due to frustration with mainstream messages about autism. We wanted to build a resource for our community that was an alternative to fear and stigma. It is also our hope that by fostering understanding and educating people about autism from a place of respect and acceptance that we can help to create a better, more accessible and more inclusive world for everyone. As the network of neurodiversity libraries grows, that hope becomes closer to a reality every day.

Currently Active Neurodiversity Libraries

**Unbound Books Autism Acceptance Library**
facebook.com/unboundacceptance

**MacDonald Autistic Pride & Neurodiversity Lending Library**
Boston, MA
facebook.com/autisticpridelibrary/

**Neurodiversity Connect**
Australia
Neurodiversityconnect.org.au

**Little Free Neurodiversity Library**
Omaha, NE
facebook.com/littlefreeneurodiversitylibrary

**The Good Sunflower Autism Acceptance Library & Resource Center**
Hammond, LA
facebook.com/goodsunflowerpower

**Neurodiversity & Parenting Library of Long Island**
Long Island, NY
facebook.com/neurodiversityandparentinglibraryoflongisland

**Neurodefiant Autistic Pride Lending Library of NOVA**
Northern Virginia
NeuroDefiant Autistic Pride Lending Library of NOVA

**Los Angeles Neurodiversity**
Los Angeles, CA
facebook.com/LANeurodiversity/

**Ed Wiley Autism Acceptance Lending Library**
Stanwood, WA
neurodiversitylibrary.org

*Lei Wiley-Mydske* and Lana Thomas of Unbound Books and also facilitate a Facebook group for people who want to bring neurodiversity libraries to their own communities. They welcome anyone interested in learning more, even if you are not sure how or when you want to start your own library.
As a queer and trans disabled activist, I’ve spent the last several years of my life thinking about my identity with the LGBTQ and disability communities because, for the past several years, I’ve felt the weight that marginalization has when you identify yourself with those communities. That’s not to say that I didn’t feel that weight before because I’ve always been queer, trans, and disabled and have always experienced barriers and discrimination. I feel the weight of marginalization more acutely now because I’ve been made more aware of it and how straight, cisgender, and abled people don’t feel what I feel or experience the same barriers.

“While there are a lot of things my socio-economic privilege gave me access to, there are some aspects of my socio-economic privilege that my sexual orientation, gender identity, and/or disabilities prevented me from accessing.”

I was privileged to grow up in an upper middle class household, but my parents never accepted my identity as a transgender man who is also autistic. While there are a lot of things my socio-economic privilege gave me access to, there are some aspects of my socio-economic privilege that my sexual orientation, gender identity, and/or disabilities prevented me from accessing. For example, in theory, I could afford nice clothes. However, since it was my parents who decided how their money was spent, I often couldn't get clothes that reflected how I wanted to express my gender identity. Also, my parents would not buy me media or other things that were LGBTQ-affirming. The only way I could get my first suit was by reasoning that it was more modest for me to wear a suit instead of a skirt or a dress while playing the drums in church on Sundays. That suit came from the women's section, however. Also, despite living in a part of town with good schools and having parents who could afford to send me to private schools, I could not fully access those schools because of ableism. In 5th grade, my rich white school refused to give me an IEP, and my parents, including my father who is a lawyer, could not get them to give me an IEP. On the other hand, because of my family’s class privilege, my family was able to thrive solely off my father's income so my mother didn't need to work and could be a full-time mother and wife. This meant my parents were able to pull me out of traditional public and private schools and homeschool me.

As I moved into adulthood, I had to face additional barriers. I became separated from my family a couple of years ago because of their lack of acceptance of my identity, so I had to find out how to support myself. The process of finding a job for myself was challenging.

Like a lot of autistic people, I especially struggled during the interview process. The majority of jobs require a candidate to pass an interview which causes a disparate impact on people on the autism spectrum who do not communicate the way candidates are expected to in interviews and have difficulty picking up on the hidden social cues that interviewers give with their questions.

One of the first jobs I applied to was with an autism organization, and I managed to land an interview. Fortunately, I had some coaching from a mentor for the interview so I was able to pass the interview. However, I was only their second choice for the job, and their first choice accepted the job. I managed to get other job interviews, but I was not able to pass through to the next round. I knew I had the skills they needed for the jobs, but I was not able to communicate in the way they were expecting well enough to answer their questions.

Employment is also difficult for transgender people. According to the National Center for Transgender Equality, one in four transgender people have lost a job due to bias, and more than three-fourths have experienced workplace discrimination. This can make a lot of trans people nervous about finding employment. What if we don't pass as the gender we identify as and get misgendered during a job interview? What if we're able to get the job, but, when we come out as trans, we get discriminated against? What if we're in the process of transitioning during our job search?

“I hope everyone will advocate for laws that protect marginalized communities.”
Because of the Americans with Disabilities Act, people with disabilities are protected from discrimination in housing, employment, education, and public accommodations, but the LGBTQ community does not have broad, inclusive non-discrimination protections yet. I hope everyone will advocate for laws that protect marginalized communities. At the federal level, you can urge your senators and representatives to support the Equality Act (H.R. 2282 and S. 1006). At the state and local level, you can urge your legislators and city council to adopt legislation banning discrimination in housing, employment, and public accommodations. While there continue to be significant and persistent barriers for people with disabilities and LGBTQ people, I believe that we can break down these barriers.

Thankfully, I have been able to find a part-time job with the American Psychological Association (APA) in September 2017. I started out in the Office on Early Psychologists which has grown to become the Office on Early Career and Graduate Student Affairs. Recently, my responsibilities have been expanded and I’ve taken on additional responsibilities. I’ve conducted extensive market research and am completing one-on-one interviews with staff to gather information about the awards, grants, and fellowships across all of APA’s offices. I am so happy that my supervisor has seen my potential and has given me a chance to show and use my skills to the fullest. He’s been very encouraging and supportive of my efforts to get full-time employment at APA or at places outside of APA. My supervisor sees me as an asset to the workplace, and, because of his accommodations, I am meeting or exceeding expectations for my job responsibilities.

“I am privileged to work in an environment that is accepting of who I am and to live in a city that bans discrimination in employment on the basis of gender identity.”

APA has a policy that anyone can use the restroom that best corresponds with their gender identity, and I’m excited that APA is going to go one step further by putting signs on bathroom doors to make the policy even more clear to all staff and to make APA an even safer place to work. My coworkers respect my pronouns, and, when I disclosed to them a couple of months ago that I was going on testosterone, they were very supportive. It was important to me that I disclosed because testosterone can affect someone’s mood and behavior as well as their personal appearance, and I did not want to have any interpersonal problems with my coworkers as a result of my changes in behavior or mood.

Fortunately, I have gotten to a space where I am able to more freely express who I am as an autistic trans man. I live in Washington, DC where there is an active and thriving LGBTQ community and disability community. I am active in the Metropolitan Community Church of Washington, DC, which is led by and for LGBTQ people, and I serve on the Panel of People on the Spectrum of Autism with the Autism Society of America in addition to serving as the Founder of Queerability, an LGBTQ and disability justice organization. I am so proud to be trans and autistic, and having access to the LGBTQ and disability communities has been a huge part of my building pride in myself.

Kris Guin is an intersectional social justice activist with a focus on the intersections of disability, sexual orientation, and gender identity. He is the president and founder of Queerability, a national grassroots LGBTQ and disability justice organization and serves on the Autism Society of America’s Panel of People on the Spectrum of Autism. He has been the Technical Assistance Coordinator for the Autistic Self Advocacy Network where he coordinated ASAN’s chapters and their Pacific Alliance on Disability Self Advocacy project. He worked as a consultant for the National LGBTQ Task Force for their 2017 national conference, Creating Change. Kris proudly identifies as autistic, queer, and transgender.
What Have You Accomplished that You Thought You’d Never Do?

I’ve become a professional mermaid, after it being my special interest for over a decade. My platform is disability, and all of my mersonas are autistic. I designed my tail with colors and based on pictures that made me happy; when designing it, I’d send a pic with exclamation points if it made me happy to the point of flapping. I think the incorporation of my autism into my mersona will cause some cute/funny situations that other mers have to fake at, such as taking the humans too literally. And I want to flap in front of autistic children and let them know that it’s okay. I want to become well known for speaking up about accessibility and disability activism.

Alice D.

I’m autistic. I spent a lifetime of abuse having to pretend I wasn’t affected by my environment, repress all rocking and eye-avoiding that could’ve made my life easier, unable to express my needs because oral speech was mandatory and never let me convey any emotional meaning (and what I said would’ve been dismissed anyway). Now I finally escaped that place, I’ve been slowly getting the trauma out of my system and learning to just be me. I officially quit forcing myself to speak, and text communication is changing my life. Like I don’t have to cry on my own every night. Like I can actually express myself. I feel possible.

Tales A.
*Tales is an autistic AAC user, aspiring writer and full-time book sniffer from Rio, Brazil. Asexual, quoiromantic, genderflux trans boy and probably some other color, he goes by he/him pronouns.*

This year has been wild! I kicked off a new business where I can delve into my special interest – music. I’m a publicist so I act as the link between artists and media, and being in a home office where I’m able to decompress/stim/autistically autism at will has changed my life. I also recently started as the Music Coordinator at my local community radio station, where I have found the most wonderful, accepting humans out there. In 2018, I finally feel like I can be myself authentically.

Liz A

I’ve become a paramedic. I did a job that requires multitasking, flexibility, and tolerance for extreme lights, sounds, smells, as well as strong interpersonal communication skills. I loved every second. I also went on to work in disability support services that further heightened my communication skills and self-awareness. My family was especially dubious at my capacity for the last job as I’ve been described as “intense” but my friends always believed in me.

Alex C.

I flunked out of university in my first year and I thought I would never go back to school, that it just wasn’t for me. I’m now back at school, taking one class per semester at community college (any more than that is too much for me), and loving it!

Ella R.

My biggest accomplishment is completing a full year as a middle school science teacher fresh out of college with no experience with that age group before day 1. I managed to stay put together through kids fighting, someone swallowing a bottle cap, running clubs based on topics I only have vague knowledge of (robotics and student council) and more girl drama than I could have ever imagined.

Matilda R.

“*What have you accomplished that you thought you would never be able to do?”*

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Matilda R.
I graduated high school and got my Associate of Science degree. I want to finish my 4 year college education at some point, given that I am only 18 units away from graduating from that.

Jennifer T.

IN EVERY ISSUE

Cummings and Goings: Creating Your Own Footsteps to Follow

BY CONNER CUMMINGS

The theme this issue is about passions that may be considered unique or as quoted "off the beaten path." This topic had me thinking of people I know that are leading. People that do not follow others' footsteps but create their own. Design their own Magic! We have four very impressive and unique to their own being – individuals that are on our cover with their stories. You do not want to miss.

We also have Carly Fulgham who is our featured person on “The View from Here.” Her journey I guarantee is worth following. Carly I am proud to say is a friend. I was fortunate enough to speak at last year’s Autism Society of America conference on a panel hosted by Barry Prizant. Everyone on the panel had their own communication styles. Barry did an excellent job accommodating mine. However, Carly sat next to me at ‘my-ask’ so I could have her assistance if needed to read my written notes to any questions that were directed to me. I did not have my own friends growing up but I have so many now I am making up for it. Most do not live close but they are true friends. Don't miss getting to know the Impressive Carly. And while you are reading Carly's view find a quick 'catch-up' on our previous View from Here person, Jacob Fuentes. He continues his journey and gives you a little sneak peek. Each issue not only will you one by one be introduced to the four fascinating individuals featured in the View from Here but you will get a brief update to continue the journey on the ones you have previously met. I am especially proud of View from Here because it was designed so we can add four new friends to our lives. How special is that. I think we can all use good people-good friends in our lives.

I am happy that I know so many friends that inspire me to be my own person. To be comfortable with My Uniquely Me! This is why I like to attend the Autism Society of America's conference and the Arc conference because every day I meet people that make me want to be my best.

A very good friend of mine Jonathan Murphy (who is autistic like me) is a Voice Over for books, commercials, movies and even amusement parks. He has a very deep interesting voice for speaking yet when he is a character he can make any person, place or thing come to life. Whatever object, animal or person he voices makes you want to meet them and intrigues and captivates your interest that you cannot stop listening. Jonathan's love for what he is accomplishing attracted me to consider other ideas and dreams for my photography and tie this camera passion to my love for movies.

"Jonathan's love for what he is accomplishing attracted me to consider other ideas and dreams for my photography and tie this camera passion to my love for movies."

Something new that has happened in my life is I am now a Still Photographer. That is a photographer who takes pictures at a set or location where a movie, documentary or television show is being filmed. I did my very first job for a documentary called ‘Othello-San’. A family friend was the Producer and Creator, Ted Adams. It was something that I have never done before and I always wanted to be a Still Photographer for a movie.

All the actors who starred in the movie were so amazing that even watching from the set I could feel every work and when I watched them I saw the story not a stage set. I learned to use my imagination to create magical picturesque moments at the movies. It was pretty hard sometimes because it was long hours and you have to stop when they do the actual filming as they yell SILENT and then ACTION and then you do not move or make a sound, but I got the hang of it.
When the filming was perfected after practice shoots they yell CUT THAT’s A WRAP. Did you know they even used my pictures on the poster they are using to advertise for the movie?

I felt the excitement for movie making magic by telling a story with my camera. I walked around the set and even up the stairs taking different angles of different scenes. It was a lot like Hollywood. It was my first time working with real actors, directors and movie magic talented people. I loved how they invited me for lunch with them and to meet them during breaks. And they gave me so much advice and RESPECT. At the very end of the shooting the director announced to the cast about me that my pictures were absolutely amazing. The Virginia Film Office said they were some of the best Still pictures they had ever seen.

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Since this date I have been asked to be the Still Photographer for two upcoming documentaries and I did a second one that was filmed with cars outside which was very different again. Each movie is different and exciting. My insides awaken as I feel the movie magic all around me.

I know other people who are also venturing into movies, acting and music. My friend Elaine Hall (link) has a school that is in California and I would love to be involved if they were closer. Our friends who were our last cover Ed, Matt and Navah Asner are taking acting and incorporating in a new facility they just opened that was mentioned in our previous issue.

Since we last spoke, me and my mom have been very active as advocates. We hosted disability forums for candidates running for Congress in the Northern Virginia area and attended and spoke at numerous events. I like to speak words I have written. Words do not freely come to my mouth so it is difficult for me to carry on a conversation but the words flow to my fingers from my mind in my own time and then I can read my words to large and small crowds and I enjoy doing this.

We also went to Disneyworld for my birthday. Something very magical happened on this trip. I was given a Key to the Kingdom and a limited edition Golden Coin with a picture of Walt Disney himself on it. The key does not really open the park but it did open my heart while I enjoyed all the magic of Disney.

“Oh, and I can’t wait to tell you what an amazing visit me and my mom had to the set of the new Wonder Woman movie. We can share our adventures after the movie comes out which is not until November of 2019. I can tell you I wrote a letter from my heart to Wonder Woman. I told her many things about what I know about her and what I have done. I told her I believe she can save the world along with my other Wonder Woman…my Mom and all of you including me can make a difference and save the world one piece one step at a time. I have not heard back from her yet but I do Believe I will!”

This is just remarkable to me that we are following our dreams and making them realities. Many of you have written books that were a dream and passion of yours. In our next issue we have some books and authors we will be mentioning. Share with us your passions, your dreams your journey to your own imagination of realities for you to make.

For me I hope this is only the beginning of my own path my own trail as I blaze along-side you to dream-hopes and desires that I cannot wait for you and I to reach!

Conner Cummings is a professional photographer in the Metro DC area. Conner speaks his written words. As an autistic self-advocate Conner changed a law in the state of Virginia named after him – Conner’s Law. Together with his mom they are working to change this law state by state. He is the 2015 Autism Society of America’s ‘Advocate of the Year’. Conner also enjoys writing for his popular Facebook page Conquer for Conner.
Tonight, I find myself in awe. This happens on the odd occasion that I step out of the routine that helps me create an illusion of “responsible” adulthood. It’s a weeknight, a Wednesday to be exact, and I am at a concert. That’s right. Smack dab in the middle of the week and I am living the dream of my sixteen-year-old self; a rock concert with no curfew. It is glorious, and I am giddy with excitement to see this band live. I sit back and take in the crowd. It makes me feel tiny and yet part of something bigger. Before I get too lost in my waxing philosophical, the lights begin to go down and the opening band takes the stage. My attention is quickly redirected, and I am reminded I am here to let go and enjoy.

“I think of John Elder Robison and his years with the band KISS. He was living his dream and following his strengths when he was creating their signature special effects guitars.”

Being at a concert as an autistic with sensory sensitivities is always a monster risk. I go armed with my ear plugs, sunglasses, and a bunch of fidgets. Concerts mean crowds too. Something I usually avoid like the plague. And for the most part, the reward for that risk pays off as the music and the lights take me away for a few hours. When live music is balanced properly in the sound system, there is no better sound in the world to me. My sensitive hearing relaxes, and goosebumps of pleasure run down my arms. When the bass doesn’t take over and the treble isn’t tinny, my brain settles, and I am free. That is why I am here, on a Wednesday. In search of that freedom.

It is why, as the opening band begins to play, the first thing I notice is how perfectly in tune the sound is. It sounds almost as clean as a studio recording. The balance between the vocals and the instruments is perfect. On cue, the goosebumps arrive. I glance down and notice that right below where I sit is the sound and light board; working its buttons and switches is a singular, concentrated, dark figure. The awe returns. Does this person know what an amazing job they are doing? Does anyone else even notice? I contemplate giving into my autistic desire to run down to the soundboard and compliment the sound person. Guessing it’s likely socially questionable, I decide against it and, instead, hope he is on the spectrum and is fully enjoying being in his zone, living his dream.

My thoughts wander now as I settle in to listen and watch the magic. I think of John Elder Robison and his years with the band KISS. He was living his dream and following his strengths when he was creating their signature special effects guitars. I look at the band and think they are too. Here it is twenty-five years later, and they are still rockin’ a large crowd in a major city. Still playing live to a crowd singing back the lyrics they wrote so many years ago. A band since they were thirteen-year-old kids dreaming about being rock stars, and here they are decades later selling out a huge venue in the middle of the week. Talk about living your dream.

“It makes me think about how many gave up living their dream because someone else told them it was foolish. I was one of those people for many years.”

I wonder how many people find themselves living their dream. How many people in this crowd are doing what they dream of with their time on this planet? It makes me think about how many gave up living their dream because someone else told them it was foolish. I was one of those people for many years. It was disheartening to have a dream life I could not figure out how to create. It made me feel lost and sad. It led to years of depression. I followed the dreams others had for me for most of my life. It was miserable. I was miserable.

These days, I am one of the lucky ones. I wake up every day and live the life of my dreams. I found love. I made a home. I have a pack. I live in my dream location with someone who loves animals as much as I do. I have a career I love. Strike that. I have a career. And most days, I am unstoppably happy. I’ve run through my bucket list and am now writing an unbucket list. I wake up almost every day grateful to be awake and alive; a dream for sure.

“Some people overcomplicate their dream lives, imagining huge salaries and an overabundance of “stuff”. Worse, many never even stop to think about what their dream life would be.”
Here is what I find funny about my dream life. It is very simple. There are no grand vacations, expensive purchases, or oversized homes. It’s just me and my pack happy to wake up every day and be in each other’s lives for whatever adventure life has in store for us. Thankful to have our basic needs met, we are a simple, happy crew. Some people overcomplicate their dream lives, imagining huge salaries and an overabundance of “stuff”. Worse, many never even stop to think about what their dream life would be. Fear keeping them trapped in apathy. Simply no longer believing in dream lives at all.

The music picks up and I can tell the opening band is ready for their last song. I get more goosebumps in anticipation of hearing this excited crowd, who no longer remembers it’s Wednesday, sing in unison to a song we have all been singing for more than 20 years. I wonder if this crowd knows they are part of someone else’s dream life. I wonder if they care. Maybe the energy felt in this arena comes from us all sharing the same dream life for a little while. The lights explode and the music crescendos as we put our collective worries aside and sing, sharing this dream life together for a night.

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**Becca Lory, CAS, BCCS** was diagnosed on the autism spectrum as an adult and has since become an active autism advocate, consultant, speaker, and writer. With a focus on living an active, positive life, her work includes autism consulting, public speaking engagements, writing a monthly blog, Live Positively Autistic, and the bi-weekly podcast that she co-hosts, Spectrumly Speaking. An animal lover with a special affinity for cats, Becca spends most of her time with her partner, Antonio Hector, and their Emotional Support Animal (ESA), Sir Walter Underfoot.

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**Will there Be a Future Beyond Acceptance?**

BY MEGAN AMODEO

Ever since a was a little girl, I have dreamed about living in a world that accepts everyone. I know that sounds extremely cliché, but for me it’s true.

I wasn’t diagnosed with autism until my mid-thirties, but from my earliest memories I remember being different. I was always the quirky girl that marched to the beat of my own drum. I had friends as a child, but I struggled to make lasting connections with most people. I didn’t mind being alone. I liked solitude and quiet.

“I was so excited to know that I am autistic, that I assumed everyone around me would also be super happy for me. That’s when I discovered that many people are not accepting.”

As a teen, friendships and dating eluded me. After I was married and had my own family, I realized my differences were beyond what normal adult women experience. It was after two of my three daughters were diagnosed with autism spectrum disorder that I realized that I was also on the spectrum. I sought out my own diagnosis and felt tremendous relief when the diagnosis was confirmed.

I finally found where I belonged.

I was so excited to know that I am autistic, that I assumed everyone around me would also be super happy for me. That’s when I discovered that many people are not accepting. My own parents disowned me. Several friends thought I just wanted attention. Others just said I was too normal to be autistic. The comments that stung the most came from people that assumed I must be faking because I could function in society just fine.
So today, almost ten years since my diagnosis, I hope for a different world.

I dream of a world that is accepting of every single person. I hope for a world where autism is seen as a beautiful spectacular difference, and not a burden. I envision a world where people are not looking for a cure for autism, but instead are embracing autism.

I long for a day when people don’t ask me if I wish my daughters weren’t autistic. I long for a day when the autism community can join together and create acceptance for all of us on the spectrum. I look forward to a day when many in the autism community stop looking for a cause and a cure and focus on ways to improve the lives of those with autism.

“I envision a world where everyone on the spectrum is not only accepted but celebrated.”

I want my daughters to live in a world where they are free to be themselves, not some manufactured version of what the world thinks they should be. I want everyone with disabilities to be able to go to college, have a job and have a family... if that’s their dream.

I want people to stop asking me how I handle raising daughters with autism. I want my daughters to be strong, independent young women who know who they are and want they want to do with their lives without boundaries.

I hope for a world where different never means less.

We, the autistic community, are capable of so much more than providing a scapegoat for the anti-vaccine community. We can be and do anything we choose. I envision a world where everyone on the spectrum is not only accepted but celebrated.

I am proud of who we are and what we can accomplish!

Megan Amodeo is an autistic stay-at-home mom with 3 beautiful daughters, two on the autism spectrum and one with ADHD. She’s been married to her neurotypical husband for almost 20 years. Prior to having children, Megan worked in special education. Today, she shares her life experiences and advice on Geek Club Books blog and in Zoom Autism Magazine.

In ‘The View from Here’ we are zooming in on four autistic individuals and where they are on their life journeys. Our Editor-at-Large, Conner Cummings, came up with the idea and the name was voted on by a group of our autistic peers. In this issue, Carly Fulgham shares her journey to motherhood. Make sure you also read Jacob Fuentes update on his search for a college at the end of this article.

Motherhood was a dream I gave up on in my twenties. Not because I no longer wanted children, but because I couldn’t imagine being responsible for another person when I could barely take care of myself. I had hit the bottom. I could eat, sleep, get groceries, watch tv and go to the doctor but that was it. I put on 80 lbs. and isolated myself in a 400 sq. ft. apartment in east Hollywood. I thought if I spent enough time thinking about it and talking about life with my therapist I could figure it out. But we couldn’t. Almost a year passed when I happened across a Time magazine article that changed everything. My psychologist knew nothing about the condition the boy in the article had either. But we fought the insurance company until the agreed to pay for UCLA to diagnose me. I had Autism, and I’ve since learned that what I had experienced has a name: autistic burnout.

With the diagnosis came more questions. What did it mean?

And so, the research began. The first book I read was Pretending to be Normal by Liane Holliday Willey. She had also lived much of her life without knowing she had an Autism Spectrum Disorder. In her case, as it is with most women on the spectrum, she wasn’t diagnosed with Asperger’s Syndrome until after one of her children was diagnosed. Reading her story gave me renewed hope. I got services from the state,
slowly worked my way back into the workplace and eventually got married.

My husband and I weren’t ready to have kids until I was already in my late thirties. After trying on our own for a couple of years, we decided to explore getting help. Right up front, I disclosed I had autism and that I would need very detailed written instructions because I’m not able to read between the lines. Due to a number of factors, we found out that we could go straight to IVF without trying other options and luckily, we have great insurance so it was affordable. A few weeks shy of the one-year anniversary of my first egg retrieval, I had an egg implanted that ended up becoming my baby boy who was born perfectly healthy in January.

**Pregnancy was another story altogether.**

There was exactly one, yes one, book about pregnancy in autistic women, and it was more of an autobiography by an autistic woman who was a doula. It was very good to read, but it was not the scientific book I’d hoped for to help me navigate the journey—and for a very good reason. There are no studies on pregnant autistic women! At least none that I could find. All of the traditional books about pregnancy were all over the map...some women experience X, some experience Y which is the opposite of X, some never experience anything remotely like X or Y. Not very helpful for someone who needs to know what to expect. I decided to treat the information as statistical variables, probabilities, which allowed me to at least take the broad expectation and parse the possibilities.

I found pregnancy and new mom Facebook groups to be very helpful, but even more so, the ones for autistic mothers. A community of women where I didn’t have to worry about asking stupid or embarrassing questions. Many of them, like Liane, didn’t get diagnosed until autism came up with respect to a child.

And then it occurred to me: There have been studies on autistic women and pregnancy. I realized that nearly every large study ever done likely had undiagnosed women with autism. Hidden within all the variability in the pregnancy books, I would find a description of my pregnancy.

“I’m sure issues related to my autism will come up from time to time, but for now I’m starting off this amazing journey into parenthood with a pediatrician with a lot of experience with autism.”

I would love to see a large-scale study done of pregnancy and childbirth that started with an autism and sensory issues screener. It would be interesting to see if any of the divergent pregnancy symptoms that seemingly have no rhyme or reason suddenly fell into nice categories.

I never felt a “flutter” but I’ve always had an interesting sense of interoception. From the very beginning of the second trimester, I could occasionally feel something that was like having my insides poked with the eraser end of a pencil. It was pretty amazing to experience how that tiny eraser grew over the months, always in the same vicinity, because my little guy was very active. As his due date approached, that was when my journey started to deviate from that of the neurotypical.

**First was the birth plan. To disclose or not to disclose?**

I’ve always been very public about my autism and my story because I want to make life easier for those who come after me. I started off my birth plan explaining the parts of my autism that might come up during labor and what that meant to the hospital staff who would be trying to do their job:

“Try not to poke or tap my skin with fingertips, it feels like you’re stabbing me with needles and leaves me with a feeling like you rubbed me with sandpaper for 30 minutes. If I get mad at you for touching me while I’m in pain, this is probably why. Also, may need to wear noise-cancelling headphones if the beeping and other noise gets to be too much…. I may have trouble processing multi-step instructions when my anxiety is heightened. I may have trouble verbalizing my needs if I am in pain or scared.”

That last bit was the most important. It let the staff know to ask me leading questions and not just expect me to pipe up if something was wrong. I ended up having an emergency c-section and the doctors and staff were amazing. The OR nurse in particular made sure that everyone in the operating room knew of my sensory differences. No one batted an eye that I wore my noise cancelling headphones. The continuity of care in recovery was remarkable as well. At each shift change, if the nurse was new, the outgoing one did a great job of explaining my sensory issues.

Here's the part that scares me the most: The countless anecdotes of women with autism losing their children at the hospital, or in custody battles, or at any other time, just because they have an autism diagnosis.
Remember, most women with autism are undiagnosed, and no one questions their competency just because they’re socially awkward, like to avoid crowds and have other “quirks”. After the diagnosis, no one says, “I knew it, she was such a bad mum.” It’s mostly, “Oh, she is a bit odd to talk to, but really a great mother.”

**But the fear and stigma persist.**

I’m sure issues related to my autism will come up from time to time, but for now I’m starting off this amazing journey into parenthood with a pediatrician with a lot of experience with autism, particularly experience with autistic girls. Not because I think my child will or will not have autism, but because I want someone who will understand that it’s ok if I don’t communicate, act, or react typically. I have read one too many stories of medical professionals with no autism experience jumping to conclusions about autistic moms. I’m committed to doing right by my boy. Everyone who meets him agrees that he’s the happiest baby, and I aim to keep it that way.

*Carly Fulgham* is a self-advocate and has a career as a Vice President at a national bank using her autistic specialty for process improvement. She volunteers as the President of Autism Society Ventura County, as the Vice President of Autism Society of California, as a member of Autism Society of America’s Panel of Spectrum Advisors, and as a board member of The Art of Autism.