

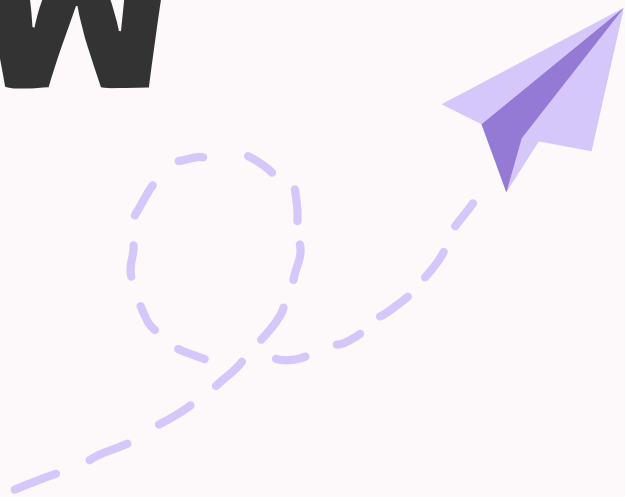
**AUTISTIC WOMEN &
NONBINARY NETWORK**

2023

**YEAR IN
REVIEW**



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2023 SUMMARY

This year, 2023, is when we're going to be building on our commitment to promote the principles of restorative and transformative justice in disability spaces.

- AWN statement of 2023 priorities, "AWN January Newsletter"

2023 served to be another year of growth, prosperity, and solidarity as we continued to uphold our goals and values surrounding transformative and restorative justice for autistic BIPOC gender minorities.

This year saw new rulings, bills, and acts that are of great harm to our community. We were vocal in our opposition to these activities and we made sure to be equally as vocal in our support for government activities that provided protection, care, and inclusion.

With a notable rise in AI technology in 2023, AWN made sure to make our stance on AI clear. We know this technology has been shown to be discriminatory towards individuals with disabilities and minorities, and we support guidelines and safeguards that would verify the safety of AI systems.

Language justice remained a priority within our work this year. Our Equity, Justice, and Representation (EJR) work also made notable achievements as we participated in training and co-authored articles, presentations, and letters that further solidified AWN as a figure within disability research and discourse.

We are appreciative and proud of all our staff members, community members, and everyone who keeps AWN going.



2023 HIGHLIGHTS & ACHIEVEMENTS

**EQUITY, JUSTICE, &
REPRESENTATION**

LANGUAGE JUSTICE

FINANCIALS

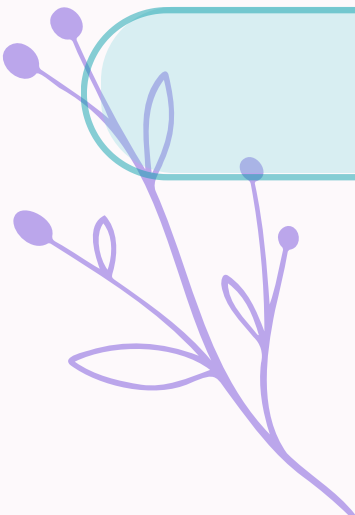
FISCAL SPONSORSHIP

RESEARCH PARTNERSHIPS

AUDITS & ACCOUNTING

SOCIAL MEDIA

NEWSLETTERS



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2023 HIGHLIGHTS & ACHIEVEMENTS

BLOG POSTS

RESOURCES

LIBERATING WEBINARS

FORMAL STATEMENTS

POLICY ADVOCACY

ADMIN UPDATES

AWN RETREAT

OTHER PROGRAMS

APPENDICES 1 & 2



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EQUITY, JUSTICE, & REPRESENTATION

EJR is AWN's Executive Advisory Board focused on Equity, Justice, and Representation. Working collaboratively with AWN and the Autistic People of Color Fund (APOC), EJER was able to fulfill AWN's focus areas of empowerment, community, fiscal sponsorship, and publications with various activities, partnerships, and events throughout the year. These included:

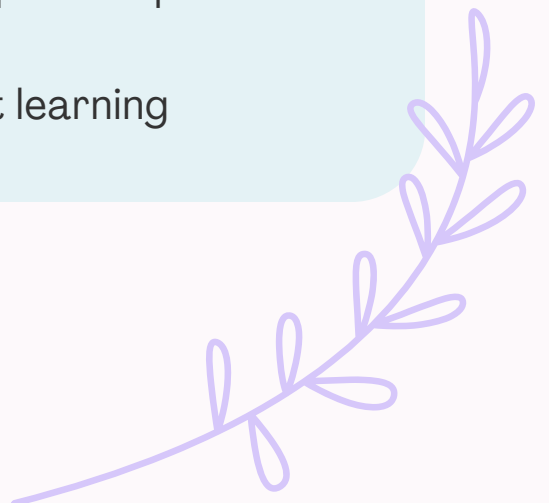
NATIONAL ONLINE TRAINING SERIES

The National Online Training Series (NOTS) is an annual training series with the National Center for Start Services focused on the mental health aspects of IDD. EJER's participation in this training will help AWN continue to create useful resources and offer mental health support.

GENDER DIVERSITY: INFINITE POSSIBILITIES

EJR attended and presented at this live Q&A session hosted by NOTS. It focused on four learning objectives:

- explaining important terminology related to gender identity
- describing how gender diversity impacts individuals who experience intellectual and developmental disabilities
- identifying the impact of different supports in persons with lived experiences
- listing resources available for constant learning and support



EQUITY, JUSTICE, & REPRESENTATION

continued:

BEST BUDDIES

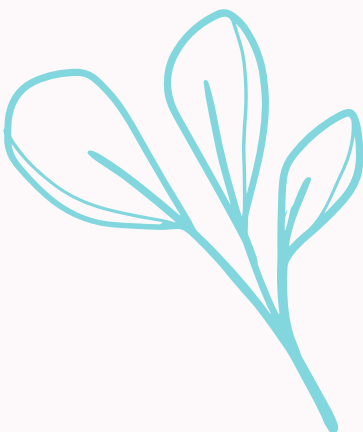
EJR participated in a training session by Best Buddies International/Institute for Corporate Productivity, DEI division. This event provided critical IDD Black Community training for 100+ US service providers and educators.

LANCET CHILD & ADOLESCENT HEALTH

EJR's Co-Chair, Morénike Giwa Onaiwu, co-authored an article on better identification of autistic people AFAB for the Lancet (the leading pediatric journal worldwide). The article proposes research and clinical directions to promote the health, development, and well-being of autistic individuals assigned female at birth (AFAB).

THE PROUD FAMILY

AWN consulted on the autism episode of *The Proud Family: Louder and Prouder* on Disney+. The episode depicts Black autistic representation as one of the family's children, Bebe, is diagnosed with autism.



EQUITY, JUSTICE, & REPRESENTATION

continued:

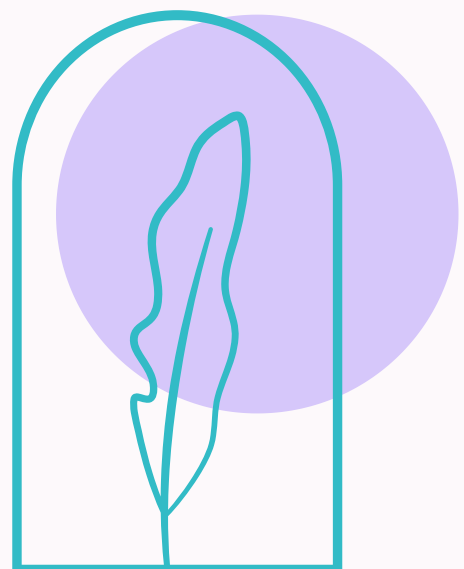
(INSAR) 2023 ANNUAL MEETING REPORT

Morénike Giwa Onaiwu also participated in the International Society for Autism Research (INSAR) 2023 Annual Meeting Report, contributing to several presentations including:

- A Systematic Review of Assent Practices in Research that Establish Evidence-based Practice for Autistic Individuals
- Promoting Wellbeing in Autistic Youth and Adults through a Positive Focus on Sexuality and Gender Diversity: Education, Clinical Practice, Research, and Policy Recommendations
- a panel discussion on Obstetric Care and Pregnancy Health Among Autistic Individuals in an Integrated Healthcare Setting in California



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LANGUAGE JUSTICE

In 2023, AWN continued to prioritize language justice in our work. This year, we expanded our efforts by opening our webinar programming to include spoken Spanish language and Spanish communication access real-time translation (CART) captioning.

As part of this effort, we connected with Sins Invalid, a disability justice-based performance project that incubates and celebrates artists with disabilities, centralizing artists of color and LGBTQ/gender-variant artists as communities who have been historically marginalized. Sins Invalid's Language Justice Coordinator, Jen/Eleana Hofer, guided AWN through the process of recruiting and developing a Language Justice and Communications Access Team for our multilingual webinar events.

Jen/Eleana also provided AWN with follow up support, reviewing our first multilingual webinar and helping us to identify ways to improve our language justice efforts going forward.



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LANGUAGE JUSTICE

This year, AWN was able to host two successful multilingual webinar events:

BROADBAND INTERNET: CIVIL RIGHTS AND DISABILITY JUSTICE

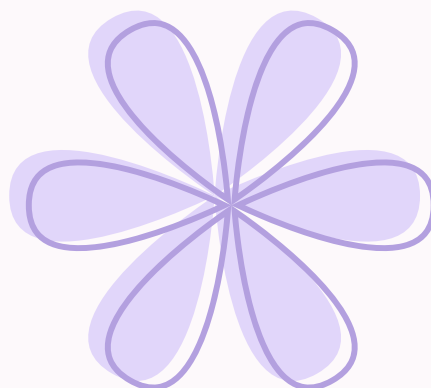
This webinar was held in English, American Sign Language, and Spanish, with both English and Spanish CART captioning provided. The webinar was a success thanks to the help of Sins Invalid and our Communications Access Team.

AANE WEBINAR

Our second multilingual webinar was an event in collaboration with the Association for Autism and Neurodiversity (AANE). When organizing this event, AWN expressed to AANE that one of our goals was to have a multilingual event that included Deaf and hearing ASL, spoken Spanish, English CART, and Spanish CART. AANE wanted to honor that goal and worked with us to ensure our webinar collaboration was multilingual.



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FINANCIALS

\$80,000+
IN GRANT FUNDING

In 2023 we continue to enjoy the support of multi-year grants from the Ford Foundation and Borealis Philanthropy's Disability Inclusion Fund. We've already received multi-year grants from the Trans Justice Foundation and California Endowment.

\$45,127
IN PRIVATE DONATIONS:

\$34,772

through Neon, from 489 donations - a nearly \$10,000 increase over last year's Neon donations

\$6,183

through MightyCause, from 221 donations - \$2,070 of this received during our Give Out Day campaign in June

\$4,172

through Facebook, from 165 one-time donations



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FISCAL SPONSORSHIP

This year, AWN celebrated fiscal sponsorship growth. We interviewed two new fiscal programs during the last quarter of 2023, and we will onboard them during the first quarter of 2024. We feel confident that we will be able to provide the same continued quality of care to all of our fiscal programs as we include our new sponsees.

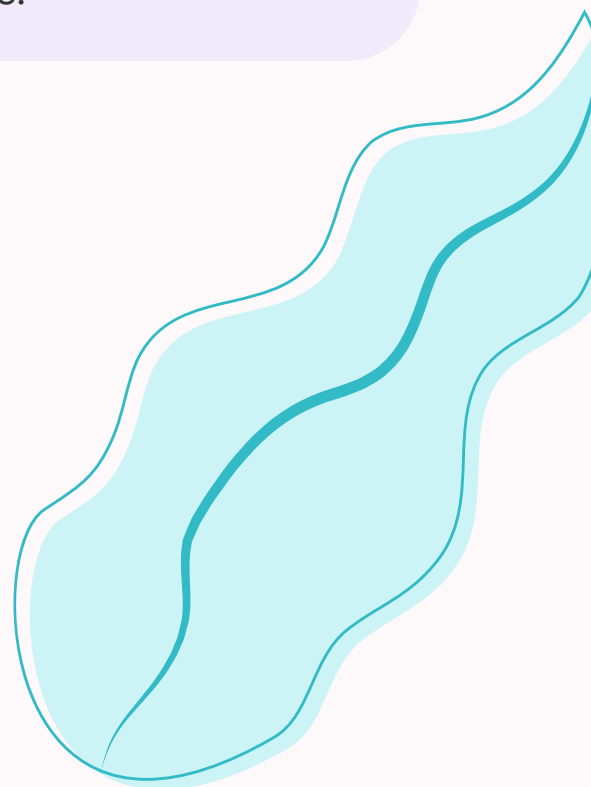
APOC FUND

The Autistic People of Color Fund continues to be one of AWN's most active fiscally sponsored programs. The APOC Fund provided \$42,717 in grants to the BIPOC community during 2023.

APOC continued with its microgrant program this year. Through the grant program, funds are provided through microgrants of up to \$500 to autistic people of color. Recipients are able to spend these funds according to their self-determined needs. In the past recipients have used funds to develop their education, buy resources such as clothing, and escape abusive relationships.



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RESEARCH PARTNERSHIPS

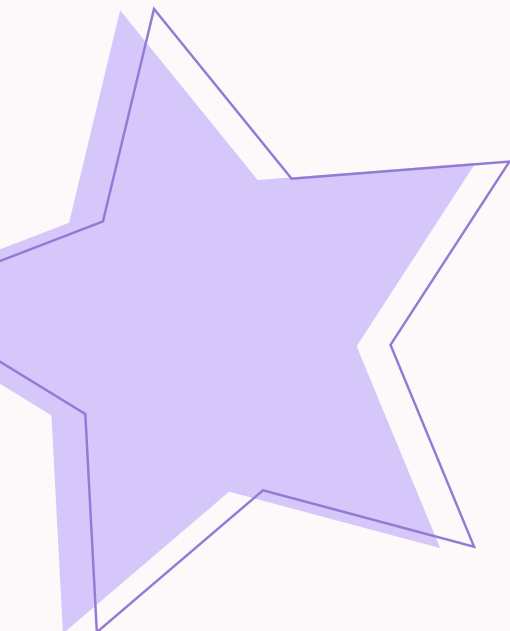
In 2023, AWN partnered with organizations on projects that include autistic people as both researchers and participants, improve our quality of life, and promote disability justice.

CHILDREN'S NATIONAL

AWN was grateful to continue our partnership with Children's National funded by NIH. Through this partnership, we are all committed to progressing autism research and improving the quality of life for autistic people.

The researchers at Children's National are made up of an interdisciplinary team that is conceptualizing and piloting the groundbreaking Self-Assessment of Autistic Traits (SAAT). SAAT is the first known autism clinical self-assessment focused on the inner experiences of autism from the views of autistic people (co-developed with autistic and non-autistic researchers).

In 2023 we signed a new 5-year contract to continue the SAAT development.



AUDITS & ACCOUNTING

AWN has hired a new accounting firm (recommended by our CPA, Imi Rashid). This new accounting firm has contracted with AWN to conduct Annual CPA reviews.

Although we are not required to submit to annual audits in the state of Nebraska where AWN is incorporated as a non-profit, we have decided to conduct these reviews voluntarily in order to provide our donors and funders with confidence in our financial practices. By using CPA reviews in lieu of traditional (and more expensive) audits, we are able to save \$10,000 annually while satisfying the needs of our funders.



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SOCIAL MEDIA ENGAGEMENT

92,000

FACEBOOK FOLLOWERS

**WITH 154 INDIVIDUAL FUNDRAISERS
RAISING \$4,172 IN ONE-TIME DONATIONS**

9,100

INSTAGRAM FOLLOWERS

**AN INCREASE OF 2,000 FROM LAST YEAR
WITH AN INCREASE IN AWN PROFILE VIEWS
OF ABOUT 39%**

45,000

**FOLLOWERS ON X
(FORMERLY KNOWN AS TWITTER)**

236

MASTODON CONNECTIONS

**A NEWER SOCIAL MEDIA PLATFORM THAT AWN
JOINED IN 2022; SINCE THEN WE HAVE NEARLY
DOUBLED OUR AUDIENCE**



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NEWSLETTERS

In 2023 we ended with a mailing list of around 6,000 people. This is an increase of about 1,000 people compared to last year's mailing list.

AWN is pleased to have almost doubled the number of newsletters released in 2023 compared to last year.

Some examples of our newsletter content include:

JANUARY

Discussed AWN goals for building on our commitment to principles of restorative and transformative justice in disability spaces; introduced new collaborations and future projects.

FEBRUARY

Celebrated Black History Month by advocating for Black people with intellectual and developmental disabilities and Black trans resistance; highlighted positive Black autistic representation via an episode of *The Proud Family: Louder and Prouder* for which AWN served as a consultant.

MARCH

Celebrated the two-year anniversary of the release of AWN's book *Sincerely, Your Autistic Child: What People on the Autism Spectrum Wish Their Parents Knew About Growing Up, Acceptance, and Identity*.



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NEWSLETTERS

Newsletter summaries continued:

APRIL

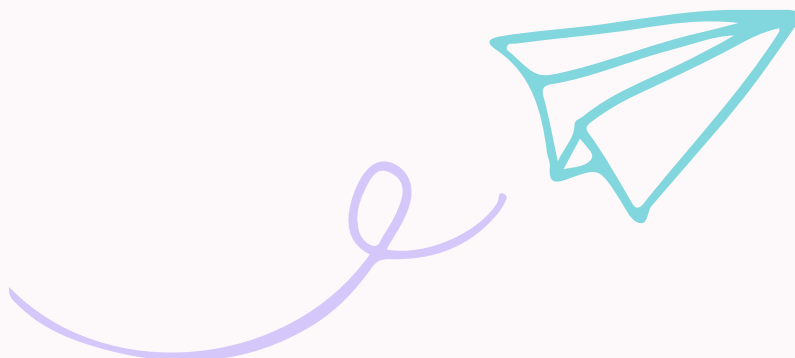
Highlighted and reaffirmed the work that AWN is doing to fight for trans rights; describes ways AWN is working to challenge anti-trans legislation while taking time to celebrate the victories we have seen for trans rights.

MAY

Celebrated Asian APIDA Heritage Month, as well as Pansexual & Panromantic Awareness Day.

JUNE

Celebrated Pride Month by sharing fundraising efforts that go towards support for neurodivergent LGBTQIAP+ people; also discussed the importance of creating inclusive art as part of AWN's work.



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BLOG POSTS

This year we published seven blog posts:

CELEBRATING BLACK TRANS RESISTANCE

This AWN post and accompanying infographic series discusses elements of the Black trans experience by providing information on their familial support and faith, healthcare discrimination and medical care, and projects that provide aid and resources.

AN AUTISTIC WOMAN'S EXPERIENCE WITH SEXUAL ASSAULT

BY KAYLA RODRIGUEZ

This post shined a light on both Autism Acceptance Month and Sexual Assault Awareness Month by providing a voice for autistic women and their experience with sexual assault. It covered personal experience, sexual assault, and mental health, and how to support those who are healing.

SENSORY & COMMUNICATION TOOLS DESERVE RESPECT

BY C.L. BRIDGE

A post advocating for the importance of sensory and communication tools while calling for more respect for these methods, and holding society accountable for ableism toward the needs of neurodivergent people.



BLOG POSTS

Blog posts continued:

CHANGELINGS & THE FOLK HISTORY OF AUTISM **BY KAYLEY WHALEN**

Our second post in April took a deep dive into the folk history of autism: the stories that reflect cultural struggles with ableism, but also how they can be used constructively as part of disability representation.

A NOTE TO PARENTS **BY AMY SEQUENZIA**

This post shone a light on the amazing work of parents and caregivers of autistic and disabled children while humanizing parents and caregivers by acknowledging the struggles they face within society.

PAID TRANS HIV PREVENTION STUDY

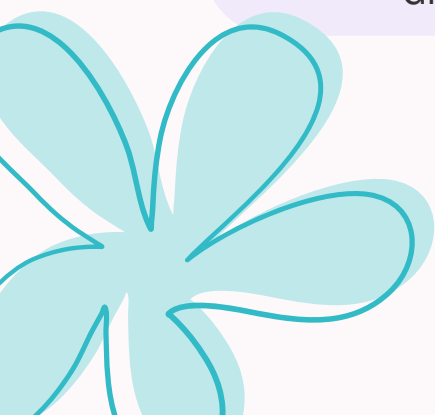
In this post AWN promoted and expressed our trust in a new study, [LifeSkills Mobile](#), which tested out an HIV prevention app for trans women and nonbinary femmes.

DAY OF THE DEAD **IN GUATEMALA AND MEXICO** **BY KAYLEY WHALEN**

This post celebrated and recognized the Day of the Dead in Guatemala, and how that country's traditions differ from those in the Mexican holiday.



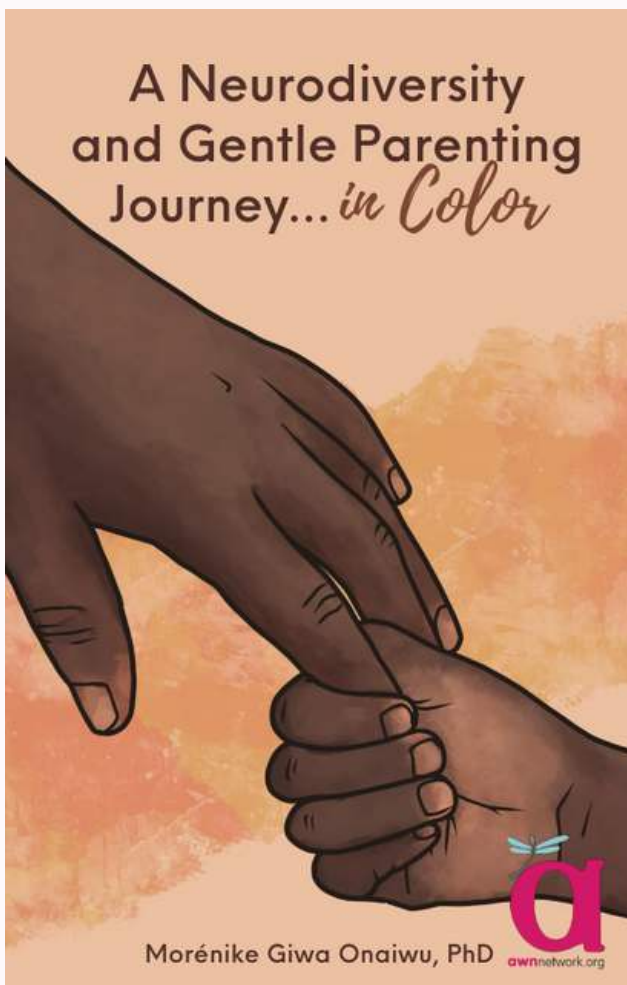
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RESOURCES

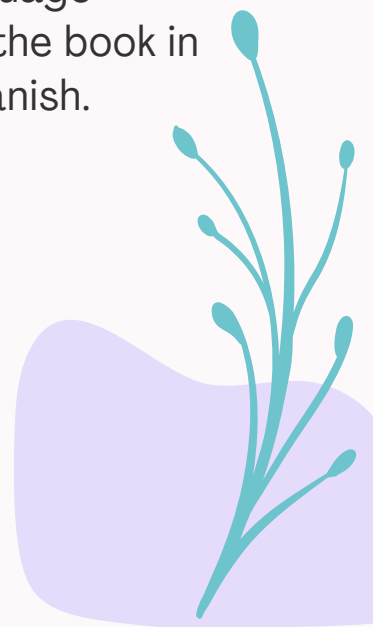
A NEURODIVERSITY AND GENTLE PARENTING JOURNEY...IN COLOR

This year, we were happy to release a new ebook titled *A Neurodiversity and Gentle Parenting Journey... in Color*, authored by Morénike Giwa Onaiwu and published through our imprint BeeDragon Press.



The book highlights the joys and challenges of neurodiversity-affirming/positive parenting while exploiting the realities of a world that is not designed for the inclusion of multicultural neurodivergent families.

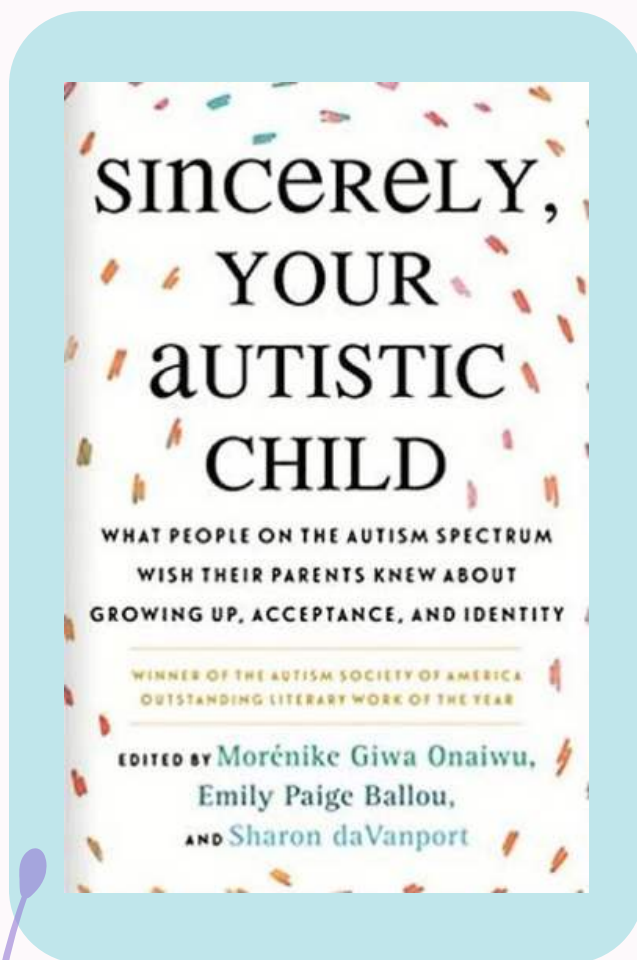
Upholding AWN's commitment to community, accessibility, and empowerment, the entire book is available for free with unlimited viewing and downloading from our website. We have also maintained our commitment to language justice by releasing the book in both English and Spanish.



RESOURCES

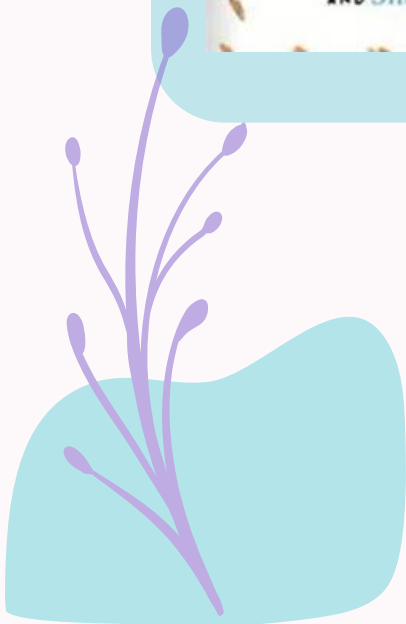
SINCERELY, YOUR AUTISTIC CHILD

Originally published in 2021, this year AWN celebrated the two-year anniversary of our book, *Sincerely, Your Autistic Child: What People on the Autism Spectrum Wish Their Parents Knew About Growing Up, Acceptance, and Identity* (SYAC).



As a diverse collection of autistic voices, SYAC continues to be a great resource for parents and caretakers of autistic children as it provides tools to make sure autistic children are valued, celebrated, and accepted.

This year, we continued to make developments to SYAC by making gendered content revisions. Our Equity, Justice, and Representation (EJR) board had extended communication with Amazon regarding problematic reviews of SYAC.



LIBERATING WEBINARS

AWN has continued to use our Liberating Webinars to showcase autistic activists, professionals, scholars, and leaders of color. Our webinars are a way for us to bring our community together while maintaining accessibility.

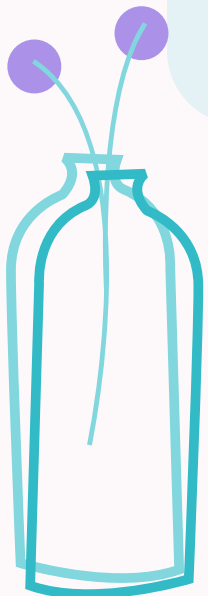
This year we presented webinars on the following topics:

BROADBAND INTERNET: CIVIL RIGHTS AND DISABILITY JUSTICE

A discussion of broadband internet and how its access is more important than ever in today's age of information. How can we create systems that allow equal and equitable access to broadband internet?

WEBINAR WITH THE ASSOCIATION FOR AUTISM AND NEURODIVERSITY

Our second webinar was a collaboration with the Association for Autism and Neurodiversity (AANE), and focused on restrictions on gender-affirming care and how these restrictions threaten the autonomy of autistic people and the civil rights of all disabled individuals. The event included an audience Q&A and recommendations on what attendees can do to make a positive difference.



FORMAL STATEMENTS

This year, we maintained our use of formal statements as a means of advocating for racial and disability justice.

Our formal statements included:

COMMENTS TO THE INTERAGENCY AUTISM COORDINATING COMMITTEE (IACC)

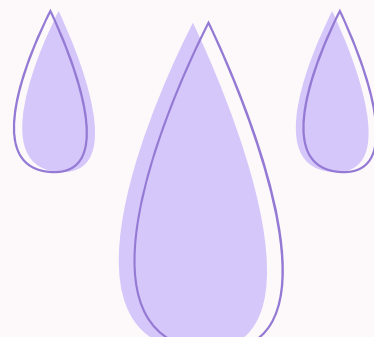
Along with the Autistic People of Color Fund (APOC), AWN encouraged the committee to prioritize funding research on the disparities and inequities in service provision and outcomes faced by autistic people of color, queer and transgender autistic people, and autistic immigrants.

ON THE MURDER OF TYRE NICHOLS

We issued a joint statement, with the APOC, on the murder of Tyre Nichols. AWN expressed empathy and support for Tyre's family in the wake of this tragedy. We also condemn the anti-Black and white supremacist systems and practices that led to Tyre's untimely death.

ON THE MASS SHOOTING IN NASHVILLE

In March, in partnership with the APOC, AWN released a statement in support of the victims of the tragic mass shooting in Nashville, Tennessee. We condemned hateful speech towards the shooter's gender identity and speculation around that person's autism diagnosis.



POLICY ADVOCACY

In 2023, we greatly increased our policy advocacy work. The policy team worked diligently on projects that aim to serve a diverse group of disabled communities, including but not limited to autistic people, people of color, transgender youth and adults, and those who hold multiple of these identities.

We signed on to eighty-eight letters, comments, and statements; endorsed seventeen bills; and supported five lawsuits. Some examples of this work include:

AI BILL OF RIGHTS

With the rise of AI technology, we felt it was important to take a stand against technology that discriminates against individuals with disabilities and BIPOC. We signed a couple of letters in support of the AI Bill of Rights, which aims to create critical safeguards requiring AI systems to be safe, effective, and nondiscriminatory.

MEDICARE'S TCET COVERAGE PATHWAY

AWN opposed the use of Transitional Coverage for Emerging Technologies (TCET) in Medicare as these pathways do not meaningfully address the problem concerning coverage and payment processes for Durable Medical Equipment, Prosthetics, Orthotics, and Supplies.

A complete list of letters, statements and amicus briefs is included in Appendix 2.



POLICY ADVOCACY

2023 policy issues continued:

WEB ACCESSIBILITY

We signed on to letters addressed to the U.S. Department of Justice outlining problems with Title II of the Americans with Disabilities Act, which deals with the accessibility of web and mobile app-based information.

Additionally, we addressed the Civil Rights Division's Disability Rights Section on a proposed nondiscrimination rule, as its compliance dates and exceptions would hinder meaningful and timely web access.

CENTER FOR MEDICARE & MEDICAID SERVICES

Several of the letters AWN signed this year involved issues with the Center for Medicare and Medicaid Services (CMS). These letters covered topics including: asking for listening sessions to allow patients to provide feedback, praising updates that improve access to dental surgical care, and extending Medicare enrollment and outreach for low-income beneficiaries.

A complete list of letters, statements and amicus briefs is included in Appendix 2.



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POLICY ADVOCACY

2023 policy issues continued:

NIMHD ADVISORY COMMITTEE

We expressed our disapproval of the NIMHD Advisory Committee's decision not to designate disabled people as a health disparity population. We called for immediate action to correct this decision as the unique ways in which disabled people access, receive, and experience health care need to be recognized.

MENTAL HEALTH PARITY & ADDICTIONS EQUITY ACT

We signed a letter from the Consortium for Constituents with Disabilities (CCD) supporting the Mental Health Parity and Addictions Equity Act (MHPAEA), which would require that individuals can access their substance use disorder and mental health benefits in parity with medical/surgical benefits.

REPRODUCTIVE HEALTHCARE ACCESSIBILITY ACT

We also signed a letter in support of the reintroduction of the Reproductive Healthcare Accessibility Act.

A complete list of letters, statements and amicus briefs is included in Appendix 2.



POLICY ADVOCACY

2023 policy issues continued:

UN SPECIAL RAPPORTEUR REEM ALSALEM

As part of our effort to call attention to the silencing of trans and nonbinary people's voices, AWN signed a letter expressing grave concern over statements made by UN Special Rapporteur Reem Alsalem about violence against women and girls that specifically excluded transwomen and nonbinary people.

H.R. 4820

We also signed a letter urging Congress to vote NO on a proposed amendment to H.R. 4820. The amendment would restrict the Equal Access Rule, which protects transgender people from discrimination in homeless shelters.

TO SENATORS CASSIDY & WARREN, AND REPRESENTATIVES KRISHNAMOORTHY & WILSON

AWN signed onto a letter to Senators Cassidy and Warren and Representatives Krishnamoorthi and Wilson requesting that “status as a student with a disability” be included as a required data element in the postsecondary student data system.

A complete list of letters, statements and amicus briefs is included in Appendix 2.



POLICY ADVOCACY

2023 policy issues continued:

HOUSE OF REPRESENTATIVES COMMITTEE ON ENERGY AND COMMERCE

We also signed a letter to the House of Representatives Committee on Energy and Commerce, which discussed autonomous vehicles and legislative provisions necessary to ensure disability accessibility and safety.

ASSISTED SUICIDE

AWN's Policy Fellow wrote and delivered an oppositional testimony regarding medically assisted suicide bills in Massachusetts.

SUBMINIMUM WAGE

AWN's Policy Fellow also wrote and delivered an oppositional testimony addressing the Department of Labor's nationwide subminimum wage program, which allows employers to pay disabled workers less than the standard minimum wage.

A complete list of letters, statements and amicus briefs is included in Appendix 2.



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ADMIN UPDATES

STAFF CHANGES

Lydia Brown was hired for a full-time policy position at another disability organization, and transitioned to a part-time Advisor role at AWN

Nancy Yang returned with expanded hours as AWN's Project Coordinator

We were also able to offer two part-time and fully compensated Policy Fellowships in 2023:

Nina Stoller became our newest Policy Fellow; Nina's experience includes a Legal Fellowship at the Coelho Center for Disability Law, working as a remote aide for a disabled adult, conducting legal research, and working at JustLeadershipUSA.

Lauren Proby became an AWN Policy Fellow; Lauren's experience includes representing students with disabilities on the Illinois State Advisory Council on the Education of Children with Disabilities, serving as a Black Girlhood Studies Fellow with Justice for Black Girls, and being the Disability Justice Lead for Youth Activism Project.



AWN RETREAT

This year we were proud to host AWN's third annual retreat in December. These retreats are a safe space for our team to come together, connect and support one another while developing new ways to grow and improve our organization.

The retreat remains a virtual event that is accessible as possible, and we had a great turnout this year: 20 people attended including staff, board members, interns, fellows, and volunteers.

The main social activity in this retreat was a 2023 Bingo game we prepared beforehand with a survey about things our participants had done over the past year. Examples of Bingo spaces included:

- started up a new special interest
- tried a new food or restaurant and loved it (or hated it!)
- binged an entire TV show in one weekend
- adopted a fur baby (or non-furry pet!)
- added something special to one of my collections

The game was a hit and helped us all learn more about each other outside of the workplace. We are excited to keep this momentum going, so along with the annual retreat, we are going to start holding monthly office hours meetups and connect with our team members in a similar fashion on a more regular basis.



OTHER POLICIES & PROGRAMS

AUTISM LENDING LIBRARIES

In 2023, AWN continued its support of the Ed Wiley Autism Acceptance Library. AWN provided \$3,750 in support, which covered the library's work on the following projects:

- a traveling sensory friendly event space
- a satellite library focused on support for LGBTQIA+ youth in the Stanwood, WA community
- the purchase of several books and resources to add to their main library

With AWN's support, the Ed Wiley Autism Acceptance Library did a lot of excellent work this year, including:

- setting up sensory friendly quiet spaces at Stanwood-Camano Pride, a local inclusive Easter Egg Hunt, the Stanwood-Camano Community Fair, and various events hosted by Stanwood-Camano PFLAG
- partnering with the Community Resource Center and Flaming Hearts Social Club, an LGBTQIA+ youth group, to create a lending library of books and resources to support LGBTQIA+ youth, their friends, schools, and families in the Stanwood-Camano Island community
- consulted with individuals at Skagit Valley College to help them find ways to build sensory friendly spaces at their El Grito/Mexican Independence Day Celebration in September of 2023

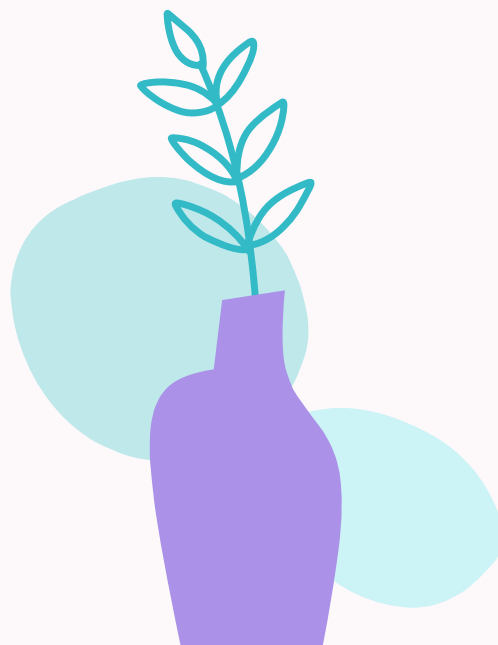


OTHER POLICIES & PROGRAMS

MEETUPS

In 2023, AWN held two social meetup events in Stanwood & Camano Island, WA. Both events were held at the Community Resource Center in Stanwood, with the August meetup being in-person only and September's meetup a hybrid in-person/virtual Zoom meetup.

AWN will continue to explore ways to safely conduct in-person meetups, along with hybrid and virtual meetups. We are excited to host more of these informal social events in the future, as they are a great way to connect with our members and community on a personal level.



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2023 HIGHLIGHTS & ACHIEVEMENTS

APPENDIX 1: LIBERATING WEBINARS

Liberating Webinars all include accommodations for accessibility and are offered to the community on our website. Awn hosted the following webinars in 2023:

BROADBAND INTERNET: CIVIL RIGHTS & DISABILITY JUSTICE

June 22, 2023.

Devan Hankerson, Research Manager at the Center for Democracy & Technology; Valerie Novack, Researcher with Utah State University; Moderator: Lydia X. Z. Brown.

In today's golden age of information, access to the World Wide Web is more important than ever. As more of our devices need access to wireless networks, the use of technology such as broadband is needed. Broadband allows multiple devices to access the internet at faster speeds. For homebound people, it provides access to the outside world.

The question lies in who gets broadband access. How are disability, race, class, and civil rights tied to who receives broadband access? Who is often left behind, and how do we create systems that allow equal and equitable access to broadband internet? Join us in conversation on this topic with DeVan Hankerson Madrigal, Valerie Novack, and Awn's Senior Advisor, Lydia X. Z. Brown.

(continued on the next page)



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2023 HIGHLIGHTS & ACHIEVEMENTS

APPENDIX 1: LIBERATING WEBINARS

(continued)

THE IMPACT OF ANTI-TRANS LEGISLATION ON THE AUTISTIC AND OTHER DISABLED COMMUNITIES

June 29, 2023.

Ma'ayan Anafi, Senior Counsel for Health Equity and Justice at the National Women's Law Center; Jay Eveson-Egler, Program manager with the Asperger/Autism Network (AANE); Heron Greenesmith, Esq, Senior Research Analyst at Political Research Associates, Policy attorney, Adjunct faculty at Boston University School of Law, Editorial Board Member at the Bulletin of Applied Trans Studies; Victoria M. Rodríguez-Roldán, national progressive policy advocate; Becca Lory Hector, Director of Training at Asperger/Autism Network (AANE).

This webinar is offered jointly by AANE (aane.org) and AWN (awnnetwork.org). Restrictions on gender-affirming care pending or enacted in multiple states not only threaten the autonomy of autistic people, but they threaten the civil rights of all disabled individuals. During this 90-minute roundtable, trans-autistic self-advocates and attorneys explain how these legislative changes disempower autistic people and the disability community. The webinar includes audience Q&A and ends with recommendations on what you can do to make a difference.

This webinar is designed for autistic people, including both adults and teens, as well as their relatives, partners/spouses, and other allies. Professionals who work with autistic people and the autistic community are also welcome.



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2023 HIGHLIGHTS & ACHIEVEMENTS

APPENDIX 2: POLICY LETTERS SIGNED

A letter to Mayor Bowser, Secretary Haaland, and Councilmember Henderson opposing homeless encampment sweeps in DC and calling for solutions that do not involve eviction, criminalization, or displacement of encampment residents.

A letter to the California Supreme Court opposing increased involuntary commitment in California under the Community Assistance, Recovery, and Empowerment (CARE) Act.

A letter to Councilmembers of the District of Columbia asking the Washington DC Department of Corrections (DOC) to establish a program allowing incarcerated individuals to exercise their right to participate in government through hearings, etc.

A letter to Congressmembers protecting the Health Care for All Patients Act of 2023 bill markup by urging support of H.R. 485, which would end the use of quality-adjusted life years (QALYs) to determine healthcare coverage.

A letter to the United States Senate Health, Education, Labor and Pensions (HELP) Committee regarding healthcare workforce shortages, Home and Community Based Services (HCBS), and community mental health services for veterans.

A letter to the United States Senate and House of Representatives Appropriation Subcommittees calling for funding of IDEA Part B Grants as a path to full funding of IDEA.

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(continued)

A letter to Washington DC Mayor Bowser and the Council of the District of Columbia in response to the abrupt closing of the Emergency Rental Assistance Program (ERAP) portal demanding further ERAP funding for FY 23 and ongoing ERAP funding as housing justice.

A CCD letter to Senator Bill Cassidy expressing three concerns with Senator Cassidy's proposed 21st Century Dyslexia Act and providing alternatives.

A letter to Congress urging full funding of the Assistive Technology Act.

A letter to the U.S. Department of Health and Human Services Centers for Medicare and Medicaid Services asking the Center for Medicare and Medicaid Services (CMS) to provide at least two listening sessions for patients to provide feedback on implementation of Medicare Part D, annual cap and cost smoothing flexibility.

A letter to the United States Senate and House of Representatives opposing the implementation of the Congressional Review Act which would immediately end the pause on student loan repayments and renege on recent public service loan forgiveness.

A letter to Medicare and Medicaid Services (CMS) praising their recent updates and commitment to improving access to dental surgical care in operating rooms and asking for the addition of ambulatory surgical centers.

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(continued)

A letter to Senate and House Appropriations Committees requesting full FY24 funding for HUD 811 Project-based Rental Assistance and Mainstream Housing Choice Vouchers, as only two federal housing programs that have an explicit purpose of providing affordable, accessible, and integrated housing for extremely low-income adults with disabilities.

A letter to the FDA to reissue its ban on electrical stimulation devices (ESDs) used to treat self-injurious or aggressive behavior.

A letter to the Biden/Harris administration urging action to protect access to mifepristone following decisions in Alliance for Hippocratic Medicine v. FDA.

A letter pushing Congress to exclude Medicaid cuts or changes that limit funding or eligibility from any debt ceiling and budget negotiations and legislation.

A letter expressing opposition to H.J. Res. 42, the resolution disapproving of the D.C. Council's passage of the Comprehensive Policing and Justice Reform Amendment Act (CPJRAA) of 2022.

A letter to the House Appropriations Committee urging approval of the highest proposed funding levels for the federal programs that support infants, toddlers, children, and youth with disabilities, their families, and the educators and other service providers who serve them without negatively impacting funding for other education programs.

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(continued)

A letter to the U.S. Department of Education containing recommendations regarding the Innovative Assessment Demonstration Authority.

A group letter to Congress asking for responsible budget answers regarding the Supplemental Nutrition Assistance Program (SNAP), Medicaid, and domestic and international discretionary spending.

A letter to Congress in support of the reintroduction of the Reproductive Healthcare Accessibility Act.

A letter to the United States Senate urging opposition to the Protect and Serve Act, which would enhance the penalties for assault/attempted assault of a police officer to mirror hate crime statutes.

A letter to the Senate Agriculture Committee with recommendations to improve Supplemental Nutrition Assistance Program (SNAP) benefits in the 2023 Farm Bill.

A letter to Congressional leadership opposing Medicaid work requirements in the Default on America Act and any debt ceiling deal.

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(continued)

A letter to the Attorney General asking for Section 508 (having federal websites be accessible) to be enforced.

A letter to the United States House and Senate in support of the Latonya Reeves Freedom Act (LRFA), which builds on the Americans with Disabilities Act (ADA) and the Supreme Court's Olmstead v. Lois Curtis decision, and asserts that people with disabilities have a right to live in their own homes and communities and to receive the services and support they need to do so.

A letter to Senators Cassidy and Warren and Representatives Krishnamoorthi and Wilson requesting "status as a student with a disability" be included as a required data element in the postsecondary student data system.

A letter to Representative Bowman expressing concerns that the Teaching Not Testing Act would allow states to sidestep gathering important data on how disabled students are performing in school.

A letter expressing grave concerns over statements made by UN Special Rapporteur Reem Alsalem on violence against women and girls which specifically excluded transwomen and nonbinary people.

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(continued)

A letter in response to CMS's recent information request on implementing Medicare Part D redesign which highlights important considerations as CMS implements the Inflation Reduction Act's \$2,000 annual out-of-pocket (OOP) cap and cost smoothing flexibility, including the need for beneficiary protections, consistent and recurring multistakeholder educational efforts, and multiple modes for beneficiaries' smoothing installment payments. The letter also notes that CMS must monitor and protect against potential unintended consequences due to broader Part D redesign, including clinically inappropriate use of utilization management techniques.

A letter to House Minority Leaders opposing any effort to use a Congressional Review Act to repeal public charge regulations that would deny entry, adjustment of status, or visas to someone likely to become primarily dependent on the government for subsistence.

A letter to the FDA advisory committee concerning its unmet need for disease-modifying therapeutics for individuals with Alzheimer's disease.

A letter in response to the U.S. Department of Education's NPRM on a technical assistance center to address significant disproportionality. The letter also lays out specific recommendations for improvement.

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(continued)

A letter to HUD containing NHLP-NLIHC joint recommendations including strengthening post-conversion compliance with RAD, restoring food policies, rescinding harmful policies, and reinstating the final rulemaking process for Section 18 proposed rules that were withdrawn in 2017.

A letter to the Chair of the House Energy and Commerce Committee advocating for legislation on autonomous vehicle regulation, research and development, and deployment at the national level. The letter advocates for a national framework for AV regulation.

A letter to Congress in support of the Orthotics and Prosthetics Patient-Centered Care Act which would exempt O&P practitioners from competitive bidding, ban drop shipping of custom orthotics and prosthetics without clinical assessment, and treat custom orthotics the way prosthetics are treated by permitting coverage of orthoses during its “useful lifetime” if there is a change in the patient’s condition.

A letter urging CMS Administrator, Chiquita Brooks-LaSure, to adopt a more refined Healthcare Common Procedure Coding System code set for intermittent catheters to ensure that individuals with disabilities and chronic conditions, particularly spinal cord injury, have access to the catheter that best meets their unique medical and functional needs.

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(continued)

A letter to Senate Finance, HELP, and House E&C expressing support for legislation to increase access to oral health coverage and care for people with disabilities.

A letter to Congress on FY 2024 appropriations, opposing cuts to subcommittee allocations.

A letter calling on Senators to cosponsor S.Res.285, the resolution establishing rights for Senate staff to unionize in response to House staffers being allowed to unionize, but Senate staffers are currently not being allowed to do so.

A letter to the Office of Special Education (OSEP) encouraging stronger revisions to proposed updates to IDEA Part B and Part C.

A letter to the Biden Administration in light of the Supreme Court decision knocking down President Biden's Debt Relief Plan. The letter urges the President to act as quickly as possible to enact the "Plan B" he announced last Friday following the decision.

A letter to Uniform Law Commissioners expressing concerns over proposed new definitions in the Uniform Determination of Death Act which could put the severely disabled at risk of being determined dead.

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A letter to the House of Representatives Committee on Energy and Commerce, as well as the Subcommittee on Innovation, Data & Commerce. The letter discusses autonomous vehicles and legislative provisions necessary to ensure disability accessibility and safety. The letter highlights which provisions to maintain, which to add, and which to strengthen. It cites a DREDF brief on ableism in autonomous vehicles, AI, and algorithms.

A letter to Representatives Debbie Dingle and Brian Fitzpatrick about “supporting continued funding for the Affordable Connectivity Program.” The program is an “FCC benefit program that helps ensure that households can afford the broadband they need for work, school, healthcare and more.”

A bipartisan letter to Congressional leadership in the House and Senate. Particularly to Senator Schumer, Senator McConnell, Speaker McCarthy, and Representative Jeffries asking Congress to condemn the white supremacist “Great Replacement” conspiracy theory rhetoric. The letter is timed with the anniversary of the El Paso shooting.

An endorsement letter to Senators Brown and Cassidy and Representatives Higgins and Fitzpatrick endorsing the SSI Savings Penalty Elimination Act.

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A letter to the Appropriations Committee safeguarding federal housing programs that explicitly support extremely low and low-income adults. The programs include Mainstream Vouchers and Section 811 Project-based Rental Assistance (PRA).

A letter to Majority Leader Schumer and Minority Lead McConnell recognizing the Role of Direct Support Professionals Act (S1332). The bill requires the Office of Management and Budget to establish a separate category within the Standard Occupational Classification system for direct support professionals.

A disability community letter to federal colleagues. The letter discusses the federal government's demonstration of a lack of understanding, failure to comply with its obligations under the Rehabilitation Act of 1973 (and they confuse it with the ADA), and explains that disabled people and people with access or functional needs are groups that overlap but are not the same. Additionally, the letter highlights the National Oceanic and Atmospheric Administration (NOAA)'s lack of 508 compliant weather maps.

A letter to Congress extending Medicare enrollment and outreach for low-income beneficiaries.

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(continued)

A letter to the White House encouraging a national calling for the AI Bill of Rights to be made binding for the federal government's use of AI systems and several other critical safeguards in the upcoming AI Executive Order.

A letter expressing concerns about CMS's notice on Transitional Coverage for Emerging Technologies (TCET). The TCET "pathway" would use various determinations to expedite Medicare coverage of certain "Breakthrough Devices." The letter discusses that these pathways won't meaningfully address the actual problem. The letter also states a need to improve coverage, coding, and payment processes for Durable Medical Equipment, Prosthetics, Orthotics and Supplies ("DMEPOS") that are not deemed "breakthrough devices or technologies."

A letter to CMS in support of the proposal to clarify and codify CMS's authority to cover "medically necessary" dental care related to cancer treatment in Medicare, encourage CMS to continue to identify additional clinical scenarios that fall under this standard, and urge CMS to ensure this coverage is implemented as effectively as possible.

A letter admonishing the NIMHD Advisory Committee for their decision not to designate disabled people as a health disparity population and requesting swift action to correct this decision.

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A letter to CMS Administrator, Chiquita Brooks-Lasure, regarding the proposed definition of the word “brace” proposing that it should not include powered devices.

A letter to the U.S. Department of Education proposing nominees for the Negotiated Rulemaking Committee, which will “decide the parameters of broad-based debt cancellation.”

A letter to Senator Menendez, Representative Smith, and Representative Cuellar urging reauthorization of the Autism CARES Act with certain requested expansions. After extensive TF discussions, these requests were kept to a bare minimum in consideration of the pending government shutdown/budget concerns.

A letter to CMS outlining concerns with the implementation of the drug negotiation process thus far, specifically requesting: Provide further information about the goals of the stakeholder meetings and ensure that feedback from beneficiaries and patient advocacy organizations is meaningfully incorporated into CMS policy decisions; Ensure that beneficiaries with the relevant condition and patient advocacy organizations are well represented in the panels; and Follow up with publicly available post-event information, noting key takeaways and with recommendations for the incorporation of information from these meetings in future guidance.

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(continued)

A letter to CMS on accountability and transparency in the IRA Drug Price Negotiation Process urging full transparency and development of guardrails against abuse of utilization management techniques by Part D plans for selected drugs.

A letter to the Department of Justice urging them to eliminate the exceptions in Title II of the Americans with Disabilities Act for web- and mobile-app-based information and services and adopt the latest WCAG standard.

A letter to the U.S. Department of Justice, more specifically the Disability Rights Section of the Civil Rights Division on the proposed rule on nondiscrimination in web accessibility. The staggered compliance dates and numerous exceptions would hinder meaningful and timely access to web- and mobile app-based services, activities, and programs for disabled people.

A letter from the Consortium for Constituents with Disabilities (CCD) outlining requirements related to the Mental Health Parity and Addictions Equity Act (MHPAEA), which requires that individuals can access their mental health and substance use disorder benefits in parity with medical/surgical benefits.

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A letter to the Social Security Administration which includes a proposed rule that “would allow SSI recipients to get more help from friends and family with housing costs without jeopardizing their SSI benefits.”

A thank you letter in support of HR 5859.

A letter urging Congress to vote “No” on an amendment to bill H.R. 4820, which would restrict the Equal Access Rule. “The Equal Access Rule protects transgender people from discrimination in homeless shelters by ensuring they can access HUD-funded shelters consistent with their gender identity.”

A letter to Congress to ensure there is no government shutdown. It calls for no harmful policy riders and no cuts to programs that disproportionately impact women, children, and LGBTQI+ people. Additionally, the letter requests additional funding for WIC and childcare.

A letter to the US Census Bureau in opposition to the proposed changes to how disability information is collected in the American Community Survey (ACS). These changes would artificially deflate the number of people with disabilities included in official Census estimates from 13.9% to 8.1% (more than a 40% reduction).

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(continued)

A letter to Congress in support of the Ensuring Patient Access to Critical Breakthrough Products Act of 2023 (H.R. 1691), which would ensure that FDA-designated breakthrough technologies are temporarily covered under Medicare during a four-year transitional period, while also establishing a pathway to make a permanent coverage determination.

A letter from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) opposing the Census Bureau's proposed changes to its disability survey methodology.

A letter from the Center for American Progress (CAP) to OMB regarding the use of AI. "We believe it is essential to meaningfully center civil rights and equity in the implementations of these executive actions. Most centrally, that means building on the AI Bill of Rights and requiring that AI systems be shown to be effective, safe, and nondiscriminatory before use."

A letter to Secretary Xavier Becerra and Health and Human Services urging the administration to implement the Section 157 proposed rule as soon as possible so that our communities can benefit from the law's protection.

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A letter from the CCD urging the US Census Bureau to pause changes to American Census Survey questions about disability, considering the serious impact and harm and asking for input from the disability community to be considered before changes are made.

A letter from the CCD Transportation Task Force which requests DOT to improve vertical access by adopting updated standards for vertical access, such as elevators, escalators, and ramps, and alerts of any outages; increase accessible communication through real time text messaging and multi-modal communication; and require functioning, accurate wayfinding navigation.

A letter from the Children Thrive Action Network (CTAN) urging Administration to not revive Title 42 and to reconsider the urgency of allowing safe asylum for children and families.

A Child Tax Credit Group letter calling on Congress to expand the Child Tax Credit to lift children out of poverty.