AUTISTIC NURSES UNITE!

NOTES FROM YOUR AUTISTIC NURSING STUDENT SISTERS

TESS CARICHNER AND
MADELEINE FERRIS

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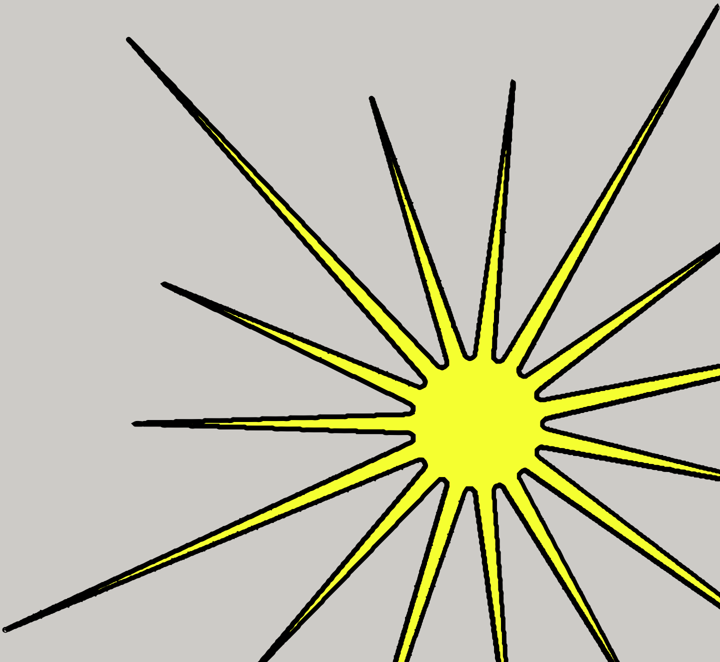


WHO ARE WE?

Something interesting about disability culture and crip wisdom is that it is not always passed down through blood-related relatives, but rather from one disabled person to another. One thing we value is disability community, which expands beyond genetics! So while we are not likely your ACTUAL sisters, we are here to provide some guidance in a sisterly way, with some wit along the way! We are thankful for our disabled elders and peer mentors who have helped us build the skills it takes to get through nursing school as autistic people. We want to introduce ourselves so you can better understand the experience we are speaking from.

* * *

Tess Carichner is a white, catholic woman from Michigan. Though not *formally* diagnosed as autistic till later in life, Tess was diagnosed with a neurodivergent condition in middle school and grew up with a brother with cerebral palsy and several family members who stutter. Tess has been immersed disability community from a young age, attending adaptive sports and learning from disabled elders. Her decision to become a nurse is influenced by her passion for disability justice and health equity. Tess is a research assistant in the Digital Accessible Futures Lab. She has gained experience in disability research and action work through the Autistic Self Advocacy Program's Autism Campus Inclusion Program, Stanford Neurodiversity Project, Sweetland Writing Center Student Advisory Board, Minding Your Mind Matters, Disability Justice @ Michigan, University of Michigan's Women and Gender Summer Fellowship Program, and various research conference presentations. Tess' special interests are collage, dogs, nature, and disability health equity communicated through creative means.

Madeleine Ferris (she/her) is a white, autistic, Jewish nursing student. She is originally from California and currently attends University of Michigan. Madeleine grew up with an autistic brother who was diagnosed as toddler but she herself was not diagnosed until she was 19. She did not learn a lot about disability culture or activism until attending university where she was able to meet and befriend fellow neurodivergent peers. Her decision to become a nurse was motivated by her own experiences dealing with health inequity growing up and wanting to implement changes to the healthcare system to minimize health disparities. Madeleine helps run Disability Justice at Michigan (DJAM) with Tess. Her special interests are the Black Plague, fiber arts, archeology, and healthcare advocacy.

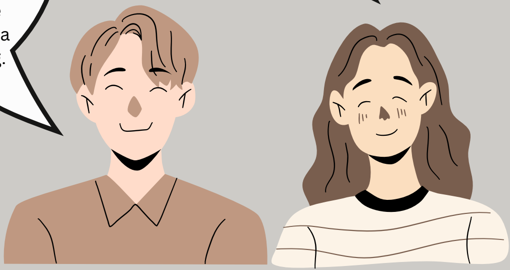
INTRODUCTION

Nursing school is hard for anyone. However, there are particular barriers faced by autistic people who additionally have many other identities that shape their experiences with academic discrimination. Structural inequities like technical standards, classes not designed with autistic people in mind, ableist social grading systems, nonadaptive scheduling requirements, and rigid rules about behavior can make matriculation for autistic nursing students difficult. While some people might say that autistic people should not become nurses, we are here to combat this ableist narrative. Autistic nurses are important. Disabled nurses are the future of anti-ableist care for our patients. Though there is a lack of published data proving our existence, we are here to assert our existence.

We believe it is imperative for disabled people to be prepared for nursing school, be accepted into nursing school, be valued for their diverse experiences, and have equitable opportunities to grow in their education and careers. We believe in the 10 Principles of Disability Justice, community action, disability pride, and that autistic people should get to be the authors of our own stories.

When I first entered nursing school, I was nervous I might be the only student in my class with accommodations. This is how it was in many of my upper-level high school classes. However, when I saw around 10% of my class was in the accommodated testing room, I felt a sense of community and belonging.
- Tess

Coming to college was the first time I began to meet fellow neurodivergent people and find a sense of community
-Madeleine



CURRENT STATE OF DISABILITY AND NURSING

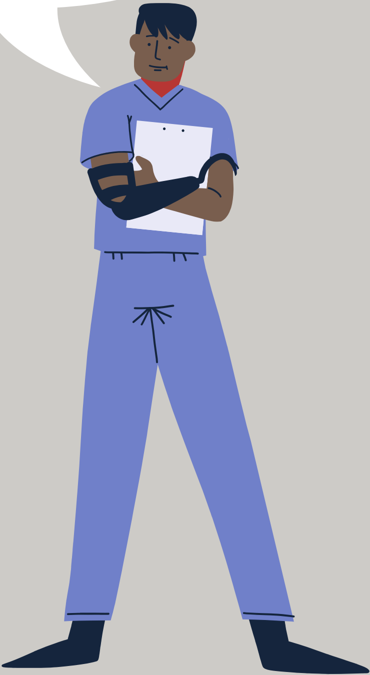
WHY DISABLED NURSES ARE IMPORTANT

We can also model positive expectations, inherently value disbaility, and share our experiences with patients.

Disabled nurses can provide **concordance** with our patients, meaning we can reflect their identities.

There is significant research showing that when healthcare workers reflect social identities of their patients, better health outcomes are more likely to occur. Concordance also promotes, “trust, satisfaction, participatory decision-making styles, positive healthcare processes and outcomes, and adherence to treatment .

Disabled people are inherently creative problem solvers. We have to problem solve regularly to access important experiences. Critical thinking is essential for nurses and we’ve got that down.



(Marks and Sisirak, 2022)

(Cooper & Powe, 2004)

WHY THERE ARE NOT ENOUGH DISABLED NURSES

Nursing was not always respected as a profession. Even today, care work is incredibly underpaid and workers are vulnerable to assault. Historically, nursing was viewed as a form of labor that women could do temporarily, in order to make a bit more money before returning back to the home. Care is considered inherent to feminine people, not something that we should be compensated fairly for. While nursing has come a long way from what many people recognize as a white-washed beginning, this is often at the cost of requirements and norms that are rooted in academic ableism. Additions to nursing school requirements are made to add layers of perceived professionalism - like technical standards. Some nurses fear that if nurses with disabilities have visibility and encouragement in the field of nursing, the public will lose respect for the field (Open the Door, Get 'Em a Locker: Educating Nursing Students with Disabilities).

In addition to disabled people, people of color have historically and presently been discriminated against in nursing education and work. For example, historically, nursing associations generally did not allow Black nurses to join. However, there were associates led by Black nurses, like the National Association of Colored Graduate Nurses (Tobbell and D'Antonio, 2022). It is important for white disabled nurses to make sure we are involved and allied in other movements to increase diversity in the field of nursing.

If you have come here to help me, you are wasting your time. But if you have come because your liberation is bound up with mine, then let us work together. - Lilla Watson

WHAT WE BELIEVE

- **Nothing About Us Without Us**
    - Simply put, disabled people can represent ourselves. While caregivers, family members, and others may support us in many ways, we are the experts of our own lived experience. Anything created to discuss our experience should not be made without consulting us and involving us in every step of the process.
- **Institutionalization erases people**
    - When people are locked away, whether in prisons or medical long-term facilties, they are being segrated from society. We are disconnected from our disability family, blood-related and not, through oppressive systems that create the social, civil, and often times physical death of disabled people.
- **Self Diagnosis is Valid**
    - Autism representation in research, education, and media is strongly tied to cisgender, heterosexual, white, young, upper middle class, men and boys. These are also the people most likely to recieve medical diagnosis. Women and gender diverse people, people of color, queer people, poor people, and other marginalized people may not have access to diagnosis or may be discriminated against in the diagnostic process. Because of this, self-diagnosis is valid. Sometimes autsitic people have learned more about autism than healthcare workers who recieved abelist healthcare education.
- **Autism is a spectrum. We must ally with autistic people across the spectrum.**
    - Some autistic people believe they are more valuable than other autsitic people. Autistic people without intellectual or developmental disability (IDD) may believe that those who do not speak, who have IDD and those who have multiply-marginalized identities, are less valuable - which is wrong. Autistic community is meant to be inclusive and supportive of all autsitic people, wherever on the spectrum they are, or whatever other marginalized identities they have.
    - The spectrum in not linear. We do not use functioning labels to describe someone’s abilities or worth.
- **All communication is important**
    - Autistic people communicate through many means. Sometimes it is through words, sounds, Augmentative Alternative Communication (typing, facial expression, American Sign Language, pointing, stimming). We continuously resist the idea that verbal communiction

THE 10 PRINCIPLES OF DISABILITY JUSTICE

Information Directly from the Sins Invalid Website (Patty Berne, 2015)

INTERSECTIONALITY “We do not live single issue lives” –Audre Lorde. Ableism, coupled with white supremacy, supported by capitalism, underscored by heteropatriarchy, has rendered the vast majority of the world “invalid.”

LEADERSHIP OF THOSE MOST IMPACTED “We are led by those who most know these systems.” –Aurora Levins Morales

ANTI-CAPITALIST POLITIC In an economy that sees land and humans as components of profit, we are anti-capitalist by the nature of having non-conforming body/minds.

COMMITMENT TO CROSS-MOVEMENT ORGANIZING Shifting how social justice movements understand disability and contextualize ableism, disability justice lends itself to politics of alliance.

RECOGNIZING WHOLENESS People have inherent worth outside of commodity relations and capitalist notions of productivity. Each person is full of history and life experience.

SUSTAINABILITY We pace ourselves, individually and collectively, to be sustained long term. Our embodied experiences guide us toward ongoing justice and liberation.

COMMITMENT TO CROSS-DISABILITY SOLIDARITY We honor the insights and participation of all of our community members, knowing that isolation undermines collective liberation.

INTERDEPENDENCE We meet each others’ needs as we build toward liberation, knowing that state solutions inevitably extend into further control over lives.

COLLECTIVE ACCESS As brown, black and queer-bodied disabled people we bring flexibility and creative nuance that go beyond able-bodied/minded normativity, to be in community with each other.

COLLECTIVE LIBERATION No body or mind can be left behind – only moving together can we accomplish the revolution we require.

TESS AND MADELEINE'S TAKEAWAYS

- Try to build a good rapport with someone in DEI leadership at your school.
- Join disability identity groups early on.
- If there are disabled people in the job you want to have, try to meet them. They will be able to mentor you in a way that fully acknowledges an important part of you.
- Sometimes people are not ready to fully realize anti-ableism overnight. The change is slow, but it is still worth instigating. Aligning expectations with what is realistic can contribute to sustainable activists.
- Take time to engage in joyful disability-related events, conversations, and media. The ableist rhetoric common in many healthcare spaces is taxing to the hope of healthcare disability activists. Nurture that hope as if it is a patient.
- Be conscious of the disabled people who are missing from your academic program. Do not forget about the people you do not see around you. It is vital that your work includes those excluded from the places you can still access.
- Always check the source of autism information you come across, even in curriculum! Is this a group with autistic leadership or at least a good relationship with leaders of the autistic self-advocate movement? If it is research - is this research that elevates the experiences of autistic people, or makes assumptions without true input and involvement of autistic people?

LIMITATIONS, INTENTIONS, AND PROCESS.

Limitations: Both of us are white, middle class students attending a highly ranked public university. The privilege allotted to us by these identities means that we cannot personally speak to the unique experiences of autistic people with other marginalized identities. However, we will try to address certain disparities as much as possible. As allies to multiplied marginalized autistics, we seek to uplift others' voices.

Intentions: This guidebook is intended to serve as a resource that recognizes the struggles of autistic nurses and gives advice based on lived experience. Perhaps students considering whether or not they are "fit" for nursing due to their neurodivergence will see that disabled nurses are important and valuable!

Process: We included information based on personal experiences, online research, and community knowledge.

ORIGINS OF THE AUTISM DIAGNOSIS

Autism is a developmental disability that affects how we experience the world around us. Autistic people are an important part of the world. Autism is a normal part of life, and makes us who we are
-Autism Self Advocacy Network

The term “Autism” was first used in the early 20th century but it wasn’t recognized as a distinct condition until 1943 by child psychiatrist Leo Kanner.

A so called “milder form” of autism was identified around the same time by Hans Asperger, an Austrian pediatrician. It became known as Asperger’s Syndrome.

Today the DSM-5 does not recognize Asperger’s as a legitimate diagnosis. Rather all forms of autism no matter the level of support needs of the individual fall under the diagnosis of Autism Spectrum Disorder (ASD)

⚠

It is important to also acknowledge the violent and ableist origins of the diagnosis. Leo Kanner incorrectly attributed autism to motherly neglect - “refrigerator mother.” With this, he attempted to justify abused operant conditioning “therapies.” Additionally, Hans Asperger was closely affiliated with the Nazi party. His research was used to justify eugenics.

⚠

(Silberman, 2022)

CONDITIONS FOR AUTISTIC PEOPLE WHEN THE DIAGNOSIS WAS CREATED

During the T4 Plan, healthcare worker-mother check-in programs were used to surveil disabled children. Information about their families, especially related to adverse experiences such as having an absent or alcoholic father were collected. Data gathered during these visits were used to locate, gather, and exterminate these disabled children. Child euthanasia programs were framed as a health service, as if murdering disabled children was a way to emancipate their parents from the responsibilities of parenthood. This murder was viewed as a “mercy killing,” insinuating that children are better off dead than disabled. Girls were often killed with less hesitation, as authorities saw disabled boys were more likely to become standardized into “volk.” One’s likelihood of being spared was based on if authorities thought one could work in the economy.

Disabled children who were not killed were put in Hitler Youth programs specifically for disabled children. Some were experimented on and others were institutionalized. Additionally, voluntary sterilizations were allowed at age 10 and forced sterilization was allowed at age 14.

How Were Nurses Part of This?

- All healthcare workers had to report disabled children from newborns to age 3 to the Reich Ministry of the Interior
- Public health ministries encouraged parents to admit their children to the program. Medical staff in these healthcare wards killed the patients through overdose or starvation.

(EUTHANASIA PROGRAM AND AKTION T4, 2022)
(Sheffer, 2018

SO... HANS ASPERGERS AND AUTISITIC IDENTITY?

You may have heard of Hans Aspergers before, a Viennese scientist. Hans Aspergers was Nazi-affiliate who believed that autistic people could be “fixed.” He called autistic people “work-shy,” indicating that our worth is tied to our ability to comply with inherently ableist capitalistic environments.

Asperger is compliant with the Nazi’s T4 plan, which was the first systematic killing plan of people during the Holocaust, aimed at murdering people with disabilities (Sheffer, 2018).

Some autistic people who were diagnosed as having Aspergers may really resonate with the name of their initial diagnosis. However, educating ourselves and others on how Autism came to be a label can uncover the roots of eugenics that hold ableist discrimination against autistic people in society.

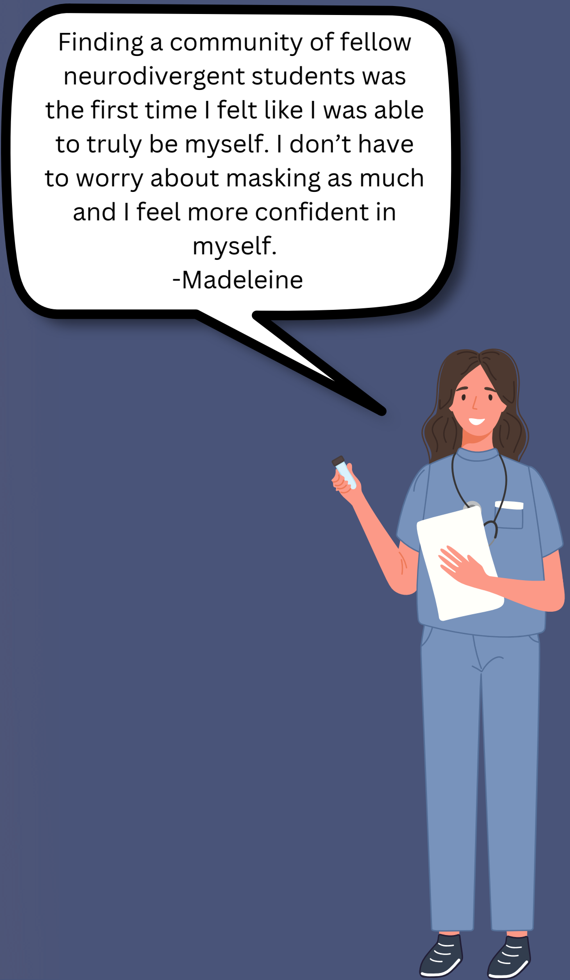
“Hmm let’s rethink that. Instead of glorifying a man who supported our extermination, let’s learn about disabled leaders and/or ancestors who fought for the improvements in access we experience as disabled decendents. Let’s celebrate Patty Bernes, Julia Bascom, Judy Heumann, Lydia X. Z. Brown, Jim Sinclair, Mia Mingus, and María Soledad Cisternas.”

“Hans Apergers is the father of Autism!”

UNDERSTANDING AUTISTIC AND DISABILITY IDENTITY

ESTABLISHING DISABILITY IDENTITY

Being a neurodivergent person living in a neurotypical world is exhausting. You may feel burnt out and tired from having to mask or maybe even feel like you can't fully be yourself around your neurotypical peers.



A great place to start looking for a community is by researching what disability groups already exist on your campus. See the organizations sections for some examples

ORGANIZATIONS

Autistic Self Advocacy Network

National Organization of Nurses with Disabilities

Disability Justice @ Michigan

LEARNING DISABILITY HISTORY

Part of proudly claiming disability identity is understanding the work of disability activists before you, and how they created the rights that you enjoy today. Many cultures are passed down through blood relatives, but not all disabled people have family members with their same disability. Disability culture is something we often have to seek out, especially if we are surrounded by nondisabled people. Learning disability history is imperative to understanding where our community comes from and how it got here.

Disability from the Beginning

Though disability was regarded differently across different cultures through time, many early beliefs of disability are related to notions of divine punishment. Public persecution, imprisonment, neglect, and segregtion were all common (A Quick History of Disability Rights, 2020).

Deinsitutionalization

In the 1960's the United States began its own version of the originally European deinstitutionaliztion movement. This movement's purpose was to get people with disabilities out of asylums and into the community with greater supports. While asylums are not commonplace in the 21st century, many see the prison-industrial complex as a transinsitutionalist replacement for asylums.

Disability Rights Movement

In the 1970s, organizations by and for disabled people (which had been in existence before the disability rights movement), won many civil rights. Some of these wins include: The Rehabilitation Act of 1973, Education for All Handicapped Children Act, and the Americans with Disabilities Act.

Disability Justice Movement

In 2005, Patty Berne, Mia Mingus, and Stacey Milbern founded the disability justice framework, which focuses on the intersecting oppressions of abelism, racism, sexism, queerphobia, classism, and more.

Finding Disabled Elders

Some histories are better recorded than others. Speaking to disabled elders, especially those with key perspectives, can help to remember legacies that are often silenced.

The Disability History Museum online is a great resource!

LEARNING DISABILITY HISTORY: COMMUNITY ENGAGED PROJECT EXAMPLE

One semester, Disability Justice @ Michigan organized a disability justice film series open to the public. We will share our flyer and some key acecss information below incase you are interested in running your own similar event to learn about disability history with others.

DISABILITY JUSTICE AT MICHIGAN FALL 2023 FILM SERIES

9/14..........Crip Camp
9/21..........Where's Molly
10/05..........My Lobotomy
10/19..........Lives Worth Living
11/2..........Willowbrook: The Last Great Disgrace
11/16..........United in Anger: A History of ACT UP

Join us for a either a virtual or select in-person screenings of these disability -focused films. Students, staff, and faculty from across campus are invited.

RSVP

https://tinyurl.com/DNAfilm2023

Access Considerations:

- captioning
- open to the public
- all either virtual or hybrid
- open slides, access information sent ahead of time
- scent free environment
- directions to bathroom
- support of alternative communication
- dim lights, letting people know about the environment ahead of time
- elevator and building directions
- map
- content warnings
- masks
- accessible entrance information

LEARNING DISABILITY HISTORY: COMMUNITY ENGAGED PROJECT EXAMPLES

Disability Justice @ Michigan was able to secure a DEI grant to fund an Anti-Ableism Library. Starting a resource like this in your community can foster disability visibility and invite others in to learn. To lessen costs and promote sustainability, we recommend buying used books. For access, provide audiobook infromation as well. Organizing a book club is a great way to encourage use of your library. We have included a book list that reflects our own library.

ANTI-ABLEIST LITTLE LIBRARY

What is Anti-Ableism?

Anti-Ableism is the rejection of norms, practices, and rules that devalue disabled people: our lives, our experiences, our dreams, and our community culture and knowledge. Anti-ableist practices assert that disabled people have the right to autonomy, self-determination, equitable healthcare access, intersectional identities, economic opportunity, community, visibility, a sense of wholeness, and more.

What is this resource?

This free library (open to students, faculty, and staff of UofM) will expose healthcare professionals (future and current) to vital information about disability identity. Through familiarizing oneself with narratives and research coming from the disability community itself, one may begin to practice more anti-ableist actions in everyday actions and thought.

How to check out/in a book:

- Scan the QR code
- Indicate if you are checking a book **out** or back **in**
- Fill out the form

Interested in getting involved with DJAM, have a question, or want to give feedback on this resource? Email carichnt@umich.edu.

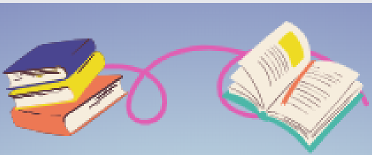
Anti-Ableist Health Library

Tips:

- advertise the library
- put the library in a high traffic area
- create a google form (can make a copy of ours) to keep track of books
- let your local library know about the resource
  - sometimes when local libraries discard older books, they become free
- create or provide audio versions of materials

BOOKS AND RESOURCES IN THE DJAM LITTLE ANTI-ABLEIST LIBRARY

- **Books**
    - Disablity Visibliity
    - Being Heumann
    - Skin, Tooth, and Bone
    - All the Weight of Our Dreams: On Living Racialized Autism
    - About Us: Essays from the Disability Series of the New York Times
    - The Exceptional Nurse: Tales from the trenches of truly resilient nurses working with disAbilities
    - Behind Our Eyes: Stories, Poems and Essays by Writers with Disabilities
    - QDA: A Queer Disability Anthology
    - The Future Is Disabled: Prophecies, Love Notes and Mourning Songs
    - Care Work: Dreaming Disability Justice
    - Decarcerating Disability: Deinstitutionalization and Prison Abolition
- **Articles and Resources**
    - The Double Burden: Health Disparities among People of Color Living with Disabilities
    - AASPIRE Healthcare Toolkit
    - Physicians' Perceptions Of People With Disability And Their Health Care
    - Nurses with Disability: Transforming Healthcare for All
    - Models of disability: their influence in nursing and potential role in challenging discrimination
    - Health Disparities for People with Intellectual Disabilities
    - First-Hand Perspectives on Behavioral Interventions for Autistic People and People with other Developmental Disabilities
    - Organ Transplantation and People with I/DD: A Review of Research, Policy and Next Steps
    - Anti-Filicide Toolkit
    - The Unacknowledged Crisis of Violence Against Disabled People
    - 10 Principles of Disability Justice



WELCOME TO OUR BOOK CLUB

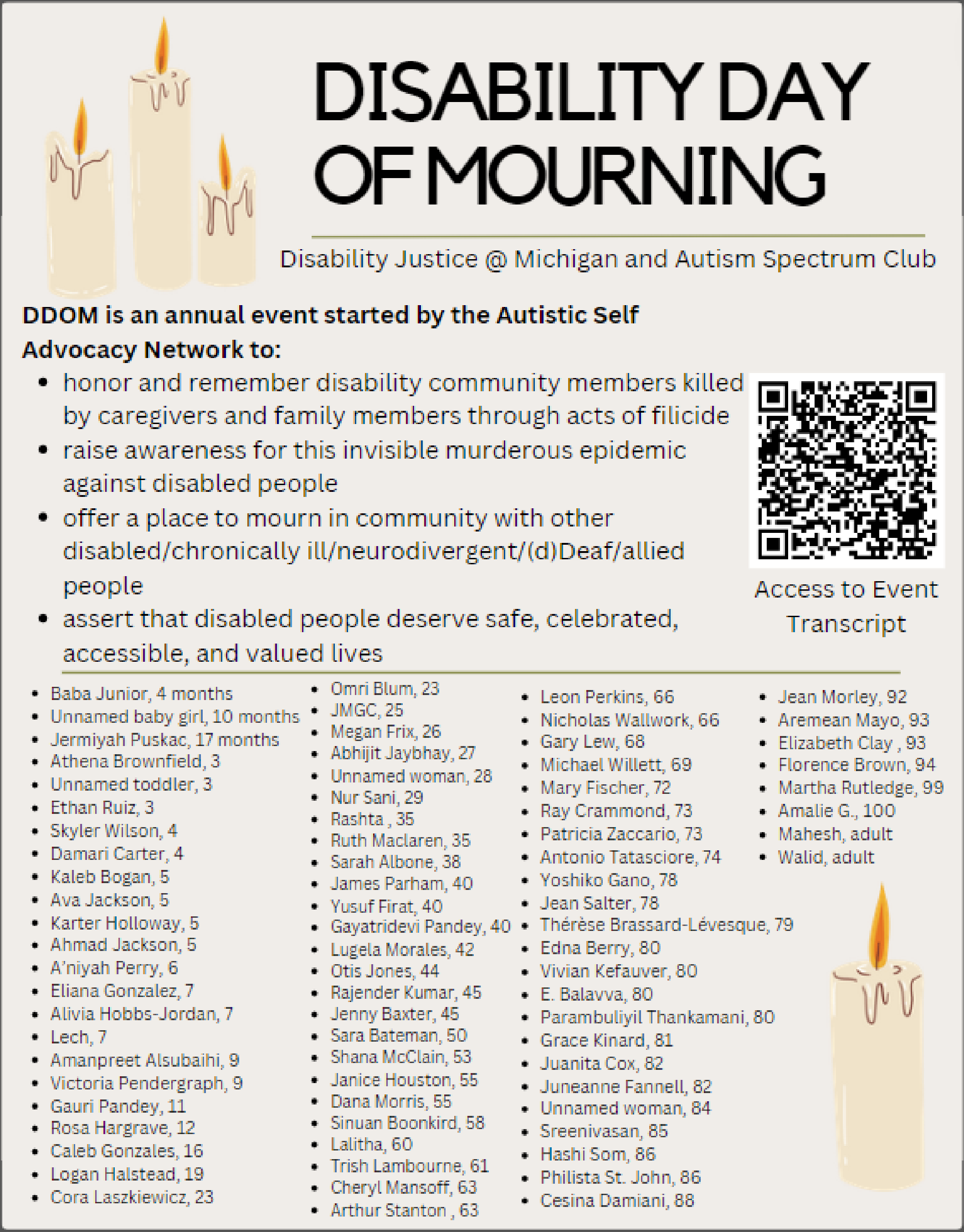
Care Work: Dreaming Disability Justice

In this collection of essays, Leah Lakshmi Piepzna-Samarasinha explores disability justice, a movement founded by Sins Invalid. Disability Justice is founded by and focused on self-determination of that centers sick and disabled queer, trans, Black, and brown people.

"Care Work is a mapping of access as radical love, a celebration of the work that sick and disabled queer/people of color are doing to find each other and to build power and community, and a tool kit for everyone who wants to build radically resilient, sustainable communities of liberation where no one is left behind. Powerful and passionate, Care Work is a crucial and necessary call to arms." - Aresenal Pulp Press

Start Week Jan 22
End Week March 18

Learn More



DISABILITY DAY OF MOURNING

Disability Justice @ Michigan and Autism Spectrum Club

DDOM is an annual event started by the Autistic Self Advocacy Network to:

- honor and remember disability community members killed by caregivers and family members through acts of filicide
- raise awareness for this invisible murderous epidemic against disabled people
- offer a place to mourn in community with other disabled/chronically ill/neurodivergent/(d)Deaf/allied people
- assert that disabled people deserve safe, celebrated, accessible, and valued lives

Access to Event Transcript

- Baba Junior, 4 months
- Unnamed baby girl, 10 months
- Jermiyah Puskac, 17 months
- Athena Brownfield, 3
- Unnamed toddler, 3
- Ethan Ruiz, 3
- Skyler Wilson, 4
- Damari Carter, 4
- Kaleb Bogan, 5
- Ava Jackson, 5
- Karter Holloway, 5
- Ahmad Jackson, 5
- A'niyah Perry, 6
- Eliana Gonzalez, 7
- Alivia Hobbs-Jordan, 7
- Lech, 7
- Amanpreet Alsubaihi, 9
- Victoria Pendergraph, 9
- Gauri Pandey, 11
- Rosa Hargrave, 12
- Caleb Gonzales, 16
- Logan Halstead, 19
- Cora Laszkiewicz, 23
- Omri Blum, 23
- JMGC, 25
- Megan Frix, 26
- Abhijit Jaybhay, 27
- Unnamed woman, 28
- Nur Sani, 29
- Rashta , 35
- Ruth Maclaren, 35
- Sarah Albone, 38
- James Parham, 40
- Yusuf Firat, 40
- Gayatridevi Pandey, 40
- Lugela Morales, 42
- Otis Jones, 44
- Rajender Kumar, 45
- Jenny Baxter, 45
- Sara Bateman, 50
- Shana McClain, 53
- Janice Houston, 55
- Dana Morris, 55
- Sinuan Boonkird, 58
- Lalitha, 60
- Trish Lambourne, 61
- Cheryl Mansoff, 63
- Arthur Stanton , 63
- Leon Perkins, 66
- Nicholas Wallwork, 66
- Gary Lew, 68
- Michael Willett, 69
- Mary Fischer, 72
- Ray Crammond, 73
- Patricia Zaccario, 73
- Antonio Tatasciore, 74
- Yoshiko Gano, 78
- Jean Salter, 78
- Thérèse Brassard-Lévesque, 79
- Edna Berry, 80
- Vivian Kefauver, 80
- E. Balavva, 80
- Parambuliyil Thankamani, 80
- Grace Kinard, 81
- Juanita Cox, 82
- Juneanne Fannell, 82
- Unnamed woman, 84
- Sreenivasan, 85
- Hashi Som, 86
- Philista St. John, 86
- Cesina Damiani, 88
- Jean Morley, 92
- Aremean Mayo, 93
- Elizabeth Clay , 93
- Florence Brown, 94
- Martha Rutledge, 99
- Amalie G., 100
- Mahesh, adult
- Walid, adult

***Because Disability Day of Mourning is founded by the Autistic Self Advocacy Network, we really wanted to engage as many autistic student leaders as possible. We contacted our school's Autistic Spectrum Club to ask if members would be willing to read names. Build coalitions with multiple disability groups. Together we are strongest and most able to support each other!

DOCUMENTING DISABILITY HISTORY @ UMICH

1973: SSD office is formed

2002: University of Michigan Initiative on Disabilities Studies (UMInDS) is formed

2009: The club Autism Speaks U is formed at UofM and is met with backlash from Autistic students advocating against Autism Speaks.

Former SSD leadership held an event pre-pandemic that discussed autism in incredibly ableist terms and spread ableist misinformation. This event resulted in protesting from students and faculty who attended.

2019: an IDEA board made up of students and faculty formed with the goal of making short and medium term goals for students with disabilities

2020: Dr. Oluwaferanmi Okanlami or Dr. O is appointed the new interim director of the SSD office. As a wheelchair user, Dr. O is the first disabled person to direct SSD

(Nieuwenhuijsen et al., 2006)

GETTING A DIAGNOSIS

Getting a professional diagnosis can be an incredibly long and difficult process, especially if you’re over the age of 18. Not every autistic person has or wants to be professionally diagnosed and that’s ok! Lets talk a bit about the pros and cons of professional vs self diagnosis.

Professional Dx

For many people, an official autism diagnosis can offer a sense of closure and peace. Most autistic people grow up feeling like there is something “off” or “wrong” with them, a diagnosis provides clarity and an explanation. It is also helpful in getting accommodations, as many places require proof of diagnosis.

It can often take several years to get professionally evaluated and can cost thousands of dollars making it inaccessible to many people. There is also the very real concern that a professional diagnosis can disqualify you from immigrating to certain countries.

Self Dx

There are many reasons someone might decide on self diagnosis. Money and time could be possible reasons, or a lack of support from family if the person is a minor or financially reliant on parents. The idea that self diagnosed autistic people are not really autistic is one that does nothing but harm the community.

However it is still important to keep in mind that many places will not accept a self diagnosis as valid proof of disability.

SELF DIAGNOSIS: WHERE SHOULD I START?

Look at the DSM-5 criteria for an autism diagnosis. It’s important to note that the criteria is slightly different for adults and children. It may be helpful to think back to your childhood or talk to parents or teachers to find out if you displayed any autistic traits as a child.

SELF SCREENING TOOLS

ADULT REPETITIVE BEHAVIOURS QUESTIONNAIRE-2 (RBQ-2A)

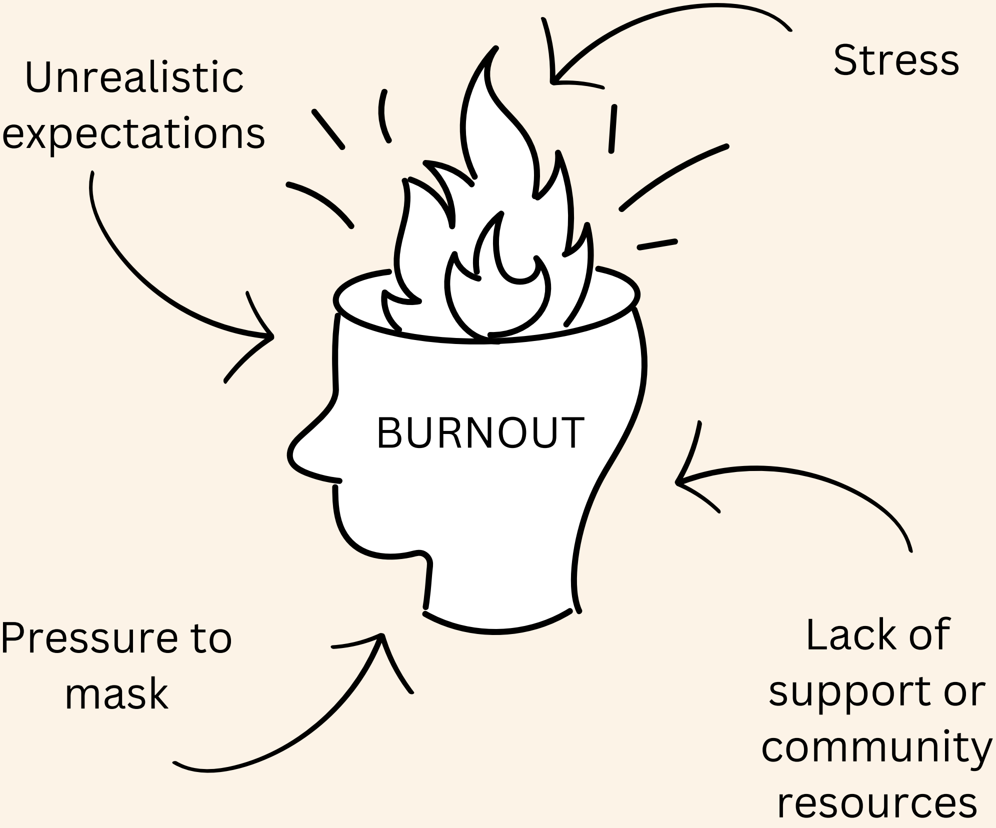
THE AUTISM SPECTRUM QUOTIENT (AQ-10)

SELF CARE AND SELF ADVOCACY

HOW TO AVOID

AUTISTIC BURNOUT

Autistic burnout is a state of intense emotional, physical, and mental exhaustion experienced by some autistic people



Unrealistic expectations

Stress

BURNOUT

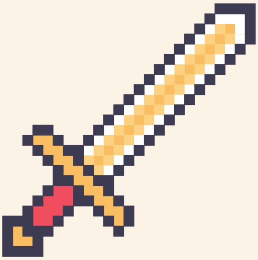
Pressure to mask

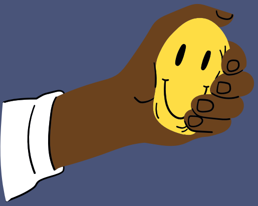
Lack of support or community resources

PICKING YOUR BATTLES

Advocacy and activism are crucial and integral to fighting ableism- they can also be draining and lead to burnout. It can feel like a constant uphill battle to advocate for your needs, especially if you attend an institution that does not prioritize the accomodation needs of autistic students. Understanding that the sole responsibility does not fall on you, and knowing when to take a step back for your own mental health are important.

Using outlines for requesting accommodations and contacting professors or employers created by other autistic people is one strategy to minimize burnout. Sample templates for accommodation requests and disability disclosures with sample language can be found on hireautism.org





AUTISTIC SELF-CARE

There are many self-care resources for allistic people. It is important to keep track of the many parts of wellness, including social, financial, occupational, environmental, spiritual, intellectual, emotional, and physical. While these are helpful and will likely benefit you, here are a few ideas for autistic-specific self-care.

Routine as Self-Care:
Many autistic people benefit from sticking to a routine. For some people, this is second nature. Sometimes, having a routine can reduce the stress of scheduling and making choices in real-time. Some examples might be building a morning routine, eating meals at the same time, showering on the same days/times, or setting up regular therapy appointments. Using a calendar or scheduling app may help you keep track of all of your tasks. You can even build self-care into your routine!

Sensory Records:
Many autistic people are sensory-sensitive, meaning that certain smells, sounds, tastes, sights, and noises are extra bothersome. Sometimes these disturbing feelings may not be easy to recognize. One way to identify these feelings and avoid them or be mindful of them in the future is through creating a sensory record. With a sensory record, you record the conditions you were in each time you have significant negative feelings. You might find that you were wearing one wool sweater every time that you cried for seemingly no reason while riding the bus. This may indicate that the tactile sensory input from wool is a trigger for you. In the future, you may switch to cotton or another fabric. You can also use a sensory record to document when certain sensory experiences feel good. For example, I (Tess), try to journal about my time in nature and by water, because I know that it provides sensory bliss for me. By acknowledging this as a fact, I am more likely to push myself to get out into nature more often.

Honoring Autism:
Often we may try to force ourselves to live allistic lives as if we do not have the needs of autistic people. While some may be able to do this for a while, burnout is imminent. Honoring autism looks like making accommodations for yourself (like limiting the number of commitments you have, keeping headphones on hand, and engaging in special interests), self-advocating, and working towards/actively loving this part of who you are.

AUTISTIC SELF-CARE PT 2

SPECIAL INTERESTS (SPINS):

Special Interests are topics that greatly interest autistic people and bring us great joy. Think about it, did you only gravitate to books about one topic as a child? Was there a specific character you resonated with more than usual? At your current age, is there a type of animal who love learning about or a specific musician you feel like you can never learn enough about? Sometimes allistic society tells us that certain special interests are not “productive.” But this is not true! Special interests are key to autistic self-care because engaging with them brings joy to us. Take time to engage with a special interest.

HAVING A SELF-CARE TO-GO KIT:

Carrying an emergency self-care kit can be helpful for doing periodic smaller-scale self-care practice. For example, in your kit you may include earplugs, headphones, lip balm, a stim toy, sun glasses, and cards with affirmations or calm down strategies to ground yourself. Of course, customizing this to your self is helpful!

THE BARE-MINIMUM CHECK-IN:

(From Tess) Personally, sometimes I have to do what I call the bare minimum check-in. This is where I check in on if I have provided myself with the most basic needs I require. For me, I think about the amount of sleep I had, whether or not I ate and drank enough, if I took my medication, if my room was in disarray, if I have been outside enough, and whether or not I had had enough alone time or time to talk with people I am close to. This can help me to make sense of how I am feeling. For example, I may feel like my typical homework assignment feels 10 times harder than usual for no reason. However, if I reflect and realize I slept only 5 hours, it makes sense and I make a plan to catch up on sleep.

Helpful Tech:

Reducing Eye Strain/Migraines: using a text-to-speech tool for long readings
Falling Asleep: Using apps with meditations, music, stories, or podcasts
Keeping Track of Tasks: Google Calendar, Google Sheets, various organizational apps

SELF ADVOCACY

“Self-advocacy means taking control of our own lives. That can mean making choices about how we live our lives, like choosing what we do at home, at school, at work, or in our relationships. It can also mean working as a community to take control over how society views disabled people, how the media talks about us, and policies that affect our lives. ASAN works on both types of self-advocacy. We want to make sure that autistic people are included in all conversations about autism, whether those conversations are about our own lives or about autistic people as a whole in our society.” -Autistic Self Advocacy Network (ASAN)

Autistic Self Advocacy Network

Often times neurotypical people advocating for autistic rights end up having their voices amplified over the voices of actually autistic people. This can be seen in the centering of parents and caregivers in conversations about autism. The goal of self advocacy is to empower and encourage disabled people to make choices for themselves. ASAN is a great resource for more detailed information about self advocacy -Madeleine

Key principals

- Nothing about us without us
- Supported decision making > guardianship
- All forms of communication are valid
- We are the experts on our own experiences

SELF ADVOCACY RESOURCES

Accessing Home and Community-Based Services: A Guide for Self Advocates

Getting and advocating for community based housing

Self Advocacy Resource and Technical Assistance Center

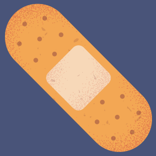
CLINICALS AND OTHER ACADEMICS

ACCOMMODATIONS

- Requesting accommodations ahead of time if possible is ideal to allow for any possible follow up needed
- Different institutions have different methods for accommodations
    - UofM accommodations are handled through the SSD office which uses the website Accommodate. Detailed instructions can be found on the SSD website

The website askjan.org provides an A to Z guide on disabilities and accommodations for both employers and individuals requesting accommodations

UNIVERSAL DESIGN FOR LEARNING AND ACCOMMODATIONS



Universal Design for Learning (UDL) means that curriculum, environment, and educational process is designed for everyone, not just the dominant culture. UDL, like accessibility, is not something we can achieve with a checklist. Instead, UDL is a continued commitment to inclusion in education. Accommodations are oftentimes individualized adjustments that make a course more accessible through retrofits, or rather, ways to edit a course after it is already designed to include someone with a disability. While accommodations can be helpful, they are a sign of disability being considered a “special” need, not an expected and valued need. It is often on the disabled student to prove their disability, get accommodations, and also make sure that those accommodations are followed.

COMMUNITY CONNECTIONS CAN HELP TO CREATE ACADEMIC CARE NETWORKS

- Creating study groups
- Sending reminders
- Creating a groupchat with disabled or accommodated students to organize in
- Making checklists to remind yourself of tasks
- Sharing knowledge and skills when studying
    - If you know how to explain something well and have time, help your community. Make community engagement and care a norm.

DISCLOSURES

In order to get accommodations, you will likely be required to disclose information about your disability. You may even be asked to provide documentation proving your diagnosis. At the University of Michigan, this information is given to the SSD office. Sometimes schools will have guidelines or policies that you do not have to disclose to your professors. It can be good to know if your schools has this rule. While we strongly encourage people to take pride in their identities, and not to be ashamed of being autistic, the unfortunate truth is that discrimination is a sad reality for many disabled people. The ADA makes discrimination based on disability illegal, however that does not mean that it doesn’t happen.

ADDRESSING DIAGNOSTIC DISPARITIES

- Autism is equally prevalent across all races , yet Black and Latino children are less likely to be diagnosed than White children and are diagnosed at an older age on average
    - this is likely due to a combination of factors including socioeconomic status and education
- Males are more likely to be diagnosed with autism than females and are more likely to be diagnosed during childhood as opposed to adulthood
    - most autism research has historically only utilized white male test subjects meaning there is very little research into how autism presents in other groups
    - autistic females tend to be more social and more likely to mask, resulting in them being diagnosed at lower rates than their male counterparts

(Disparities in the Diagnosis and Care of Autism, 2020)

ALL ABOUT CLINICALS

- Overwhelming Environments
    - The hospital can be overstimulating at times, there are constant alarms going off, people talking, and bright lights.
- Many clinical instructors and nurses have different ways of doing things and they may teach you different methods for nursing skills.
    - It can be frustrating and challenging when there is no one “right” answer.
- Disability rhetoric
    - Conversations about disability are often heavily medicalized.
    - Nurses may talk about disabled patients using ableist language, especially in pediatrics with autistic patients.
- Clinical accommodations
    - You must be able to perform all required tasks with or without reasonable accommodations.
    - What nursing schools considers reasonable accommodations varies.
- Maybe I Don’t Want to Work in a Hospital...
    - While nursing school make lead you to believe that you must be a med surg nurse, this is simply not true. The clinical area is not the end all be all. Nurses work in administrative, research, consulting, and educational roles. Many nurses in clinical work do not work in hospitals. While it is important that any disabled nurse be able to practice where they want, just know that some areas are more inherently accessible.

NURSING CURRICULUM

Medical vs Social Model of Disability

Nursing curriculum tends to center the medical model of disability with very little discussion of other models

The medical model views disability as an impairment that is inherently pathological with the goal being to "cure" the disabled individual.

The social model views disability as a part of one's identity, disability is the result of a person's environment failing to match their needs.

Ableist Content

Unfortunately, not all textbooks are up to date and sometimes contain inaccurate and even offensive content. Many professors are open to learning and growing if this is brought to their attention, but some may not be. Most courses have anonymous evals and ways to make suggestions if you do not feel comfortable directly discussing it.

(Olkin, n.d.)

RESOURCE ROUNDUP

GENERAL AUTISM MEDIA AND RESOURCES

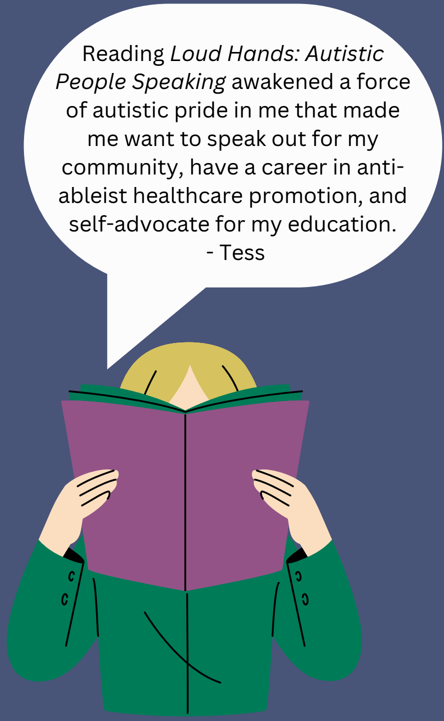
AASPIRE Toolkit

This online resource provides information for autistic adults and their healthcare team. Information such as healthcare rights, health promotion, associated conditions, worksheets, checklists, and best practices for caring for autistic patients are all available.

* * *

BOOKS BY AND FOR AUTISTIC PEOPLE

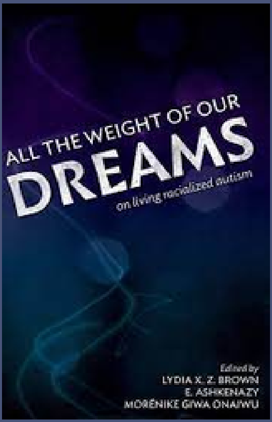
The books *And Straight on Till Morning*, *Loud Hands: Autistic People, Speaking*, and *All the Weight of our Dreams: On Living Racialized Autism* are all collections of essays written by autistic people.



Reading *Loud Hands: Autistic People Speaking* awakened a force of autistic pride in me that made me want to speak out for my community, have a career in anti-ableist healthcare promotion, and self-advocate for my education.
- Tess

Loud Hands
autistic people, speaking

And Straight on Till Morning
Essays on Autism Acceptance
Brought to you by:
ASAN
AUTISTIC SELF ADVOCACY NETWORK



ALL THE WEIGHT OF OUR DREAMS
on living racialized autism
Edited by
LYDIA X. Z. BROWN
E. ASHKENAZY
MORÉNIKE GIWA ONAIWU

UOFM SPECIFIC RESOURCES

College of LSA Disability Navigators (mostly for employees)
- Address climate as it relates to LSA employees with disabilities
- Support efforts to increase the accessibility of LSA
- Raise LSA disability community awareness
- Respond to LSA disability equity issues

Services for Students with Disabilities
- Facilitiates accommodation process
- Offers information about study abroad accommodations and campus accessiblity
- Provides academic support programs, adaptive sport opportunities, paratransit, and proctored testing

Disability Culture @ UM
- Students, staff, faculty, alumnx, & allies building prideful community centering disability culture, as it intersects with our other identities

Disability Justice @ Michigan
- Originally Disability Nursing Association, DJAM organizes disabled students and our allies to learn about disability culture/history, build community, and take action against ableism.

Disability Advocacy Coalition of Health Professionals
- Teach cultural competency in disablity healthcare communication
- Show how students can be part of combatting medical ableism
- Support providers (future and current) in medicine with disability

Medical Students for Disability Health and Advocacy
- Connecting likeminded people
- Educating mdeical school about disability and chronic illness
- Disability health initiatives
- Strengthening voices of medical students with disabilities and allies

Society for Disabled and Neurodivergent Students
- Social events, educational opportunities, advocacy, and emotional support in a group made for disabled, neurodivergent, chronically ill students

Autism Spectrum Coalition @ UM
- Low committment, low stress social club to meet other autsitic people, promote wellness, and provide help in navigating struggles

Council For Disablity Concerns
- creating community that:
  - respects disability
  - honors individual needs
  - makes everything accessible

DISABLED, NEURODIVERGENT, D/HOH, AND CHRONICALLY ILL NURSE INFLUENCERS

- Ryann Mason - nurse, wheelchair user
- Andrea Dalzell - nurse, wheelchair user
- @nursekenzie - nurse, neurodivergent
- @myautsiticnurse - nurse, autistic
- Sarah Massey, @rahmassey21 - pediatric oncology nurse, chronically ill
- Asha, @justmecameil - pediatric nurse, Deaf
- Kaela, @mikaelchavezt - nurse, Deaf
- Freya, @the.tubie.nurse - nursing student, chronically ill
- Kendra, @kayandt1 - hospice nurse, chronically ill
- Jami Fregeau, @theneurodivergentnurse - nurse, neurodivergent
- Michael Taylor, @thefullspectrumnurse - nurse, ADHD, autistic

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