



Activism Through Content

Western Massachusetts
Disability Studies Conference
Friday, February 26, 2016

Housekeeping

- Everyone all set?
- Anyone need a printout?
 - Slides available now at <https://app.box.com/AWN>
 - Will post as a blog post on <https://www.autismwomensnetwork.org>
- Don't forget conference rules
- Ringers for cellphones and other devices (and vibrate) should be off
- Feel free to move about

Me



- **Amanda Gaul Worboys**
- Finance Director, AWN
- Commercial and residential real estate attorney
- Boston College, A&S '99, BA (Political Science)
- Boston College Law School '03, JD
- Carroll Graduate School of Management, Boston College '03, MBA



More Housekeeping

- **Content Warnings** - ableism, sexism, misogyny/gender disparity, racism, classism; eating disorders, depression, anxiety, meltdowns; brief mention of Nazi's and some awful mid-twentieth century psychiatry; discussion of people's awful behavior on social media



More House



- **One Term of “Art”**
 - “Spoons” or “Tokens”
 - Required Reading: The Spoon Theory, by Christine Miserandino www.butyoudontlooksick.com
- **One Personal Language Preference**
 - AWN uses identity first language. Both respects and affirms the worth and value of our Autistic identities
 - For a review of this topic, see <http://www.autistichoya.com/2011/08/significance-of-semantics-person-first.html>

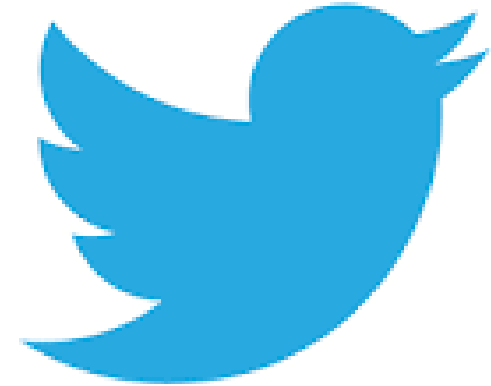


Agenda

- About AWN and Our Mission & Values
- AWN's Content Strategy
 - Social Media Landscape
 - Our Strategy & Statistics
- AWN's Publications
 - What Every Autistic Girl Wishes Her Parents Knew
 - All the Weight of Our Dreams: On Living Racialized Autism
- DIVERgent: when feminism and disability collide
- Questions?

Questions?

- Please tweet them to me at **@Autism_Women** and I will review and answer at the end of the presentation (or in the next few days)
- Want to connect offline? Please email me at **amanda@autismwomensnetwork.org** and I will review and answer in the next few days



Who's Here?



Autism Women's Network (AWN)

- Mission Statement
 - The mission of the Autism Women's Network is to provide effective supports to Autistic women and girls of all ages through a sense of community, advocacy and resources.
- Autistic led organization, by women & non-binary people
- Founded in 2010, incorporated in 2011 and received 501(c)(3) status in 2013



AWN's Values and Commitments

- Gender & LGBTQIA
 - AWN both recognizes and affirms each individual's gender identity and sexual orientation.
 - We recognize that gender is not a binary, and that one can identify with “woman” and a non-binary gender at the same time.
 - We will not tolerate abusive behavior based on perceived or actual gender identity and presentation.
- <http://autismwomensnetwork.org/autism-womens-network-statement-on-gender/>

AWN's Values and Commitments

- Race
 - AWN is committed to recognizing and celebrating diversity and the many intersectional experiences of Autistic women.
 - **Committee on Autism & Ethnicity** was established to highlight the impact of race and culture on Autistic lives, and to find ways to support individuals and families in multiple marginalized populations.
- <http://autismwomensnetwork.org/about/>

AWN's Values and Commitments

- Neurodiversity
 - Certain conditions, including Autism, are natural variations of the human genome, and are not defects that need to be fixed.
 - The ability of an individual should be augmented and supported, and the disability should be mitigated and accommodated.
 - The worth of the individual is not less because of Autism, and that Autism is an important and valuable aspect of a person's identity.
- <http://www.autistichoya.com/p/introduction-to-autism-faqs-of-autism.html>



AWN's Values and Commitments

- AWN has focused on challenging societal attitudes about the worth of disabled lives.
 - **Actually in our Community Guidelines:** “All comments suggesting that abuse or murder of disabled people is caused by lack of services will be deleted and the commenter will be banned. Lack of services or supports for disabled people and their caregivers is never a justification for murder or abuse.”
 - Bringing attention to harmful therapies & interventions
 - Disability Day of Mourning
 - Solidarity with other marginalized communities

AWN's Work

- What is Autism?
- Who's diagnosed? Who's not being diagnosed?
- What's the prevalence, really? (Is there an epidemic?)
- What causes autism?



AWN's Work

- What is Autism?
 - Neurological variation that occurs in 1-3% percent of the population; classified as a developmental disability.
 - Not a new condition and exists in all parts of the world, in both children and adults of all ages.
 - Diagnosed based on observation by a diagnostician or team of diagnosticians (e.g. neuropsychologist, psychologist, psychiatrist, licensed clinical social worker, etc.).

AWN's Work

What is Autism?

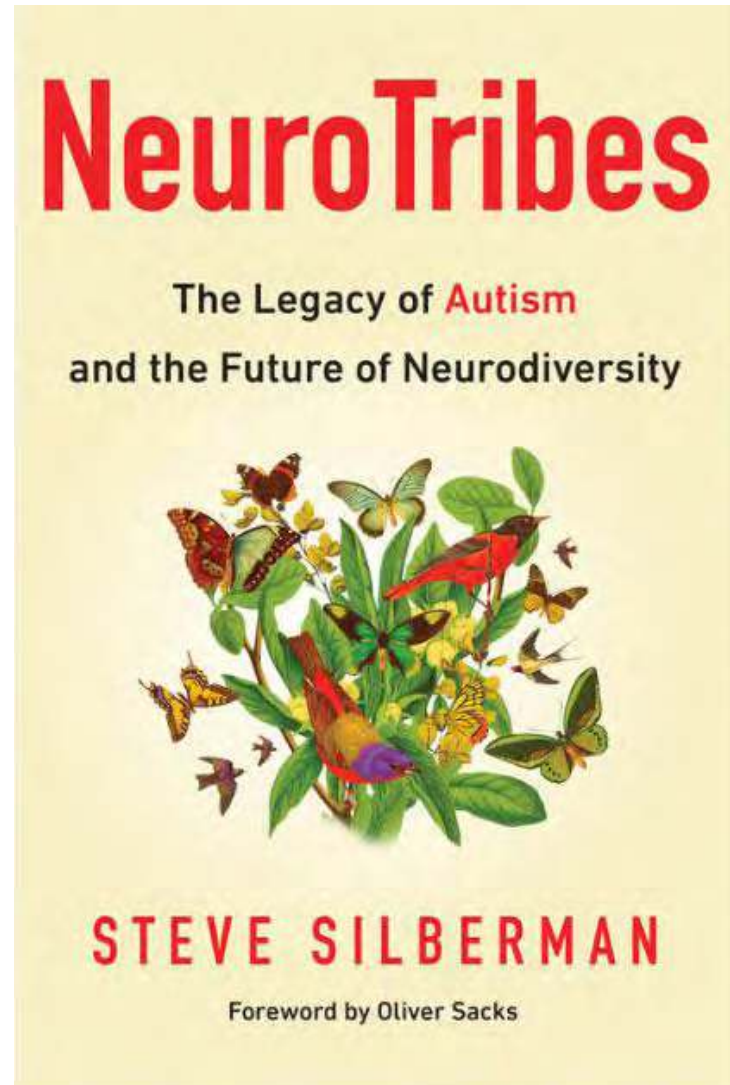
- Shared characteristics typical of autism
 1. Different sensory experiences
 2. Unique/non-standard ways of learning and problem solving
 3. Deeply focused thinking and passionate interests in specific subject
 4. Atypical, sometimes repetitive movement
 5. Need for consistency, routine and order
 6. Difficulties in understanding and expressing language as used in typical communication, both verbal and non-verbal; may struggle to use language to explain emotions and internal state
 7. Difficulties in understanding and expressing typical social interaction.

AWN's Work

- Myths About Autism
 - Autistic People Don't Have Empathy
 - Empathy is the ability to look at someone, consider what they are feeling and then feel it for yourself.
 - The problems are with reading body language and facial expressions to get the full message
 - In fact, Autistics can feel TOO MUCH – Intensive World Hypothesis.
 - Autistic People are More Violent
 - Actually more likely to be a victim of a crime.
 - All Autistic People are Savants – FALSE!
 - Only about 1 in 10

AWN's Work

- What is Autism?
 - 20th Discovery
 - Some History



AWN's Work – Some Context

- Who's diagnosed? Who's not being diagnosed?
 - Boys in the US were almost 5 times more likely to be identified with ASD than girls.
 - 1 in 42 boys were identified with ASD. 1 in 189 girls were identified with ASD. (CDC Figures)
 - Worldwide, the most widely reported male-to-female ratio for ASD is 4:1 (Halladay, 2014).
 - There is a range from 2:1 to 16:1.
 - National Autism Society (NAS) in UK: adults using services were 3:1 male/female; NAS schools were 5:1.

AWN's Work

- White children were more likely to be identified with ASD than black or Hispanic children. Black children were more likely to be identified with ASD than Hispanic children
 - 1 in 63 white children were identified with ASD.
 - 1 in 81 black children were identified with ASD.
 - 1 in 93 Hispanic children were identified ASD.
 - 1 in 81 Asian or Pacific Islander children were identified with ASD.

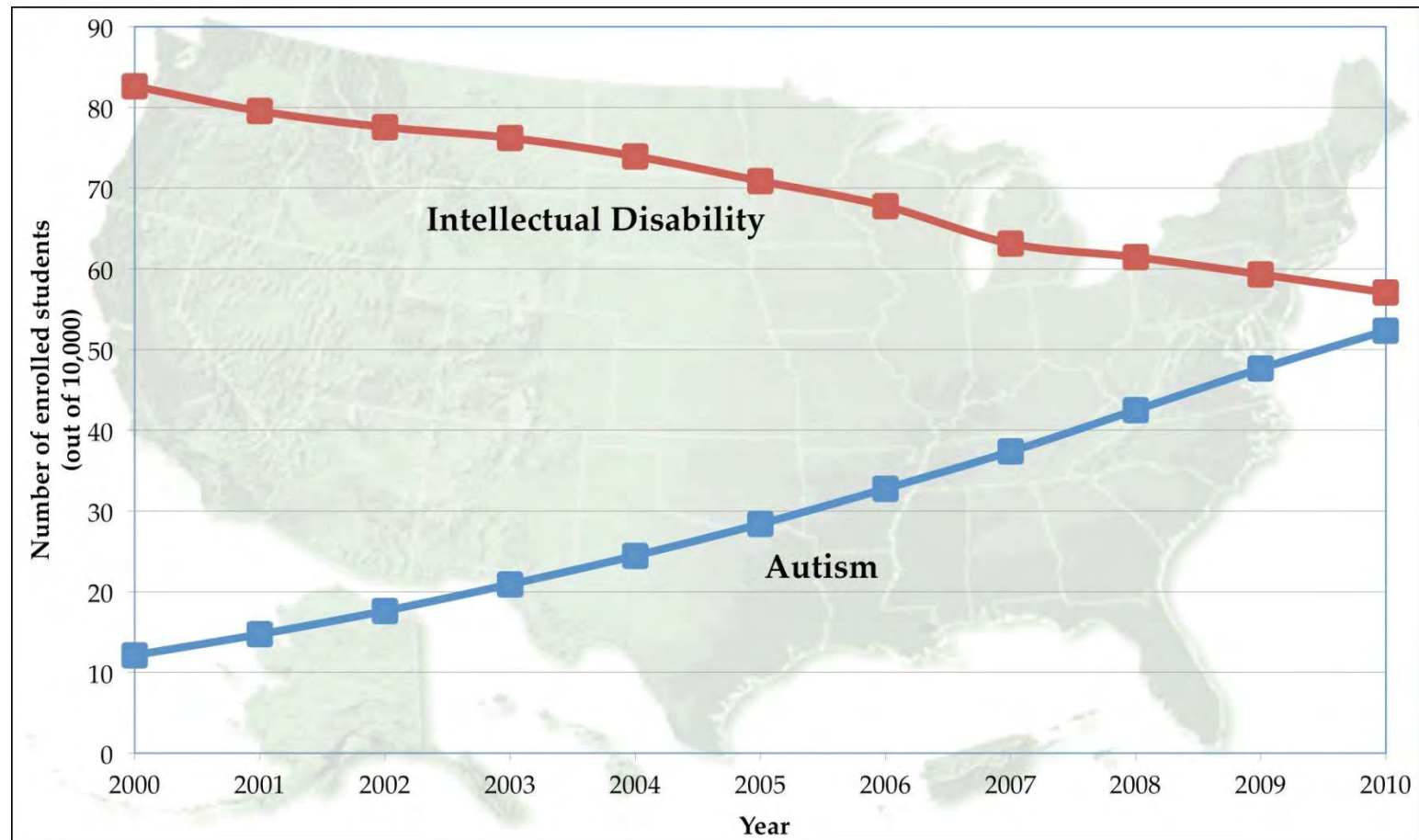
Source: CDC

AWN's Work

- What's the prevalence, really? (Is there an epidemic?)
 - CDC says 1 in 68 children (8 year olds) based on data from a dozen or so sites - high of 1 in 17 in Alabama to 1 in 45 in NJ.
 - Boys are 1 in 42 vs Girls at 1 in 189 (5:1)
 - UK and other countries actually survey multiple ages, including adults.
 - Scientists who study this say ...
 - Anywhere between 0.5 and 3 percent
 - Simon Baron-Cohen, a researcher at the University of Cambridge, found a 2.3 percent prevalence in college-age participants

AWN's Work

- What's the prevalence, really? (Is there an epidemic?)
 - Here's the reality



AWN's Work

- What causes autism?
 - Autism is about the brain and what causes Autism affects the brain's development.
 - It's NOT behavioral or caused by upbringing or emotional deprivation.
 - Evidence suggests cause is due to complex genetic factors
 - Multiple studies on twins and families suggest that Autism is genetic, and that multiple genes and parts of several chromosomes are involved in producing phenotypic traits of Autism in an individual.
 - Compounded by interaction of genes and by interaction with environmental factors.



AWN's Work

- What causes autism?
 - Some theorize Autism results from the interaction of humans and aliens.
 - [http://aliensandchildren.org/Cause of Autism Epidemic.htm](http://aliensandchildren.org/Cause_of_Autism_Epidemic.htm)
 - See also <http://pleiadians.net/>
 - There are many less credible theories about environmental causes, such as the vaccine-causation hypothesis, which stems from a 1998 paper by Andrew Wakefield.
 - Other theories were that thimerosal or mercury in vaccines causes Autism. There is no scientifically valid evidence to support this theory.

AWN's Work

- Why add our voice?
 - Toxic/ableist environment anyway
 - Lots of tension and disagreement
 - Public narrative re Autism generally dominated by parents
 - And there is something very real about the gender disparity/gender differences



AWN's Work

- How is Autism different in women and girls? Why the difference in diagnostic rates?
 - Conceived by Dr. Asperger as a male thing – autism as an extreme male brain.
 - Interplay with gender differences and societal expectations

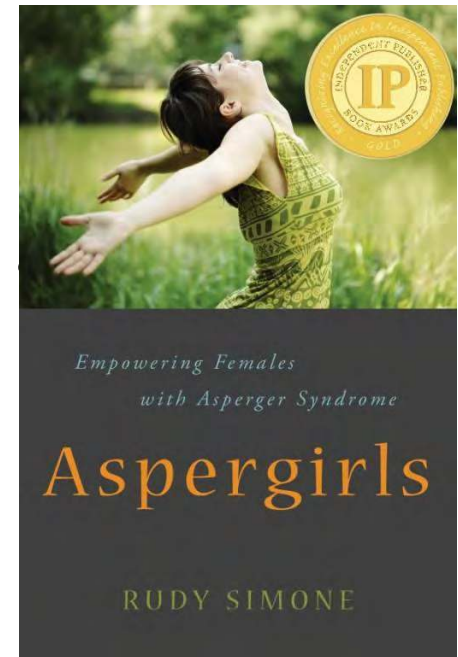


AWN's Work

- How is Autism different in women and girls?
Why the difference in diagnostic rates?
 - Doctors already use different growth charts for boys and girls
 - Screened brothers and sisters of children with ASD, found 40% of girls with “very high” levels of autistic symptoms had NOT been diagnosed with ASD
 - Suggests a gender ratio of 3 boys to every 2 girls

AWN's Work

- How is Autism different in women and girls?
 - An Emerging Female Profile (Lai, Lombardo, Auyeung, Chakrabarti, & Baron-Cohen, 2014).
 - Increased social imitation skills,
 - A desire to interact directly with others,
 - A tendency to be shy or passive,
 - Better imagination,
 - Better linguistic abilities developmentally,
 - Interests that focus on animals or people.
 - See also help4aspergers.com — Rudy Simone's site (author of *Aspergirls*)



AWN's Work – Some Context

- How is Autism different in women and girls?
 - More expressive in face and gestures than male counterparts
 - Especially when happy: flapping, clapping, singing, jumping, dancing – also more socially acceptable
 - May appear youthful for her age – in looks, dress, behavior, tastes
 - Eccentric personality

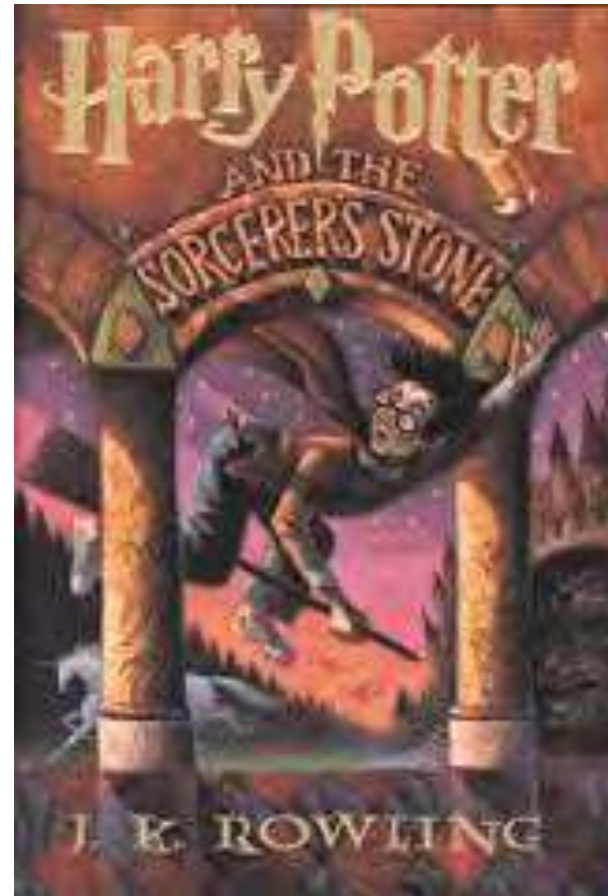


AWN's Work – Some Context

- How is Autism different in women and girls?
 - **Increased social imitation skills,**
 - May be chameleon-like; may not have a strong sense of identity
 - Better socializing in small doses; may appear skilled but really a 'performance'
 - Copying and mimicking can be exhausting and may lead to more women being diagnosed with mental health issues.
 - Tends to dress comfortably (due to sensory issues) and not spend much time on grooming; hair likely to be 'wash and wear'

AWN's Work – Some Context

- How is Autism different in women and girls?
 - **Better imagination,**
 - Can enjoy reading, films as a retreat or refuse, often sci-fi, fantasy, children's books
 - Can be very elaborate and serve as an escape



AWN's Work – Some Context

- How is Autism different in women and girls?
 - **Interests that focus on animals (horses!) or people.**
 - Interests less obtrusive, more practical.
 - Male presentation is a strong stereotype.
 - Tend to be similar to those of other girls – not seem as unusual.
 - It's the quality and intensity that differentiates these girls.



AWN's Work

- How is Autism different in women and girls?
 - Prone to having a temper and crying meltdowns, even in public (males tend not to cry)
 - Hates injustice and hates being misunderstood; words and actions often misunderstood
 - May be very outspoken, may get fired up when talking about passions or interests



AWN's Work

- How is Autism different in women and girls?
 - Sexuality & Gender:
 - Similar interest in sex and strength of sexuality as NT's
 - Higher rates of asexuality
 - Lower rates of heterosexuality/higher rates of homosexuality (significantly more so than males)
 - Studies have found higher rates of Autism amongst transgender individuals (5.5%)

AWN's Work

- How is Autism different in women and girls?
 - Less likely to receive early correct diagnosis
 - may have been seen as gifted, shy, sensitive, etc,
 - Girls who are dx'd tend to have additional difficulties
 - More likely diagnosis as bipolar or manic depressive

AWN's Work

- How to ally (v) with Autistics?
 - No cure talk
 - Don't mention or validate any talk about vaccines or aliens
 - Support and amplify voices of autistic people, not their parents/caregivers
 - Stop parents/caregivers from sharing private details about Autistic children
 - Ask them if identify first language or person first language
 - Stand up against sympathy or apologies for those who kill (or try to kill) their disabled children
 - Believe us when we bring up barriers and obstacles, like sensory challenges.
 - Presume competence for all forms of communication.
 - Lead by example



AWN's Work – Our Activities

- Ongoing – website/blog, social media content
- Healthcare Provider Survey
- Welcome Packets
- Community Events
- Committees (2)
 - Race
 - DIVERgent: when feminism and disability collide

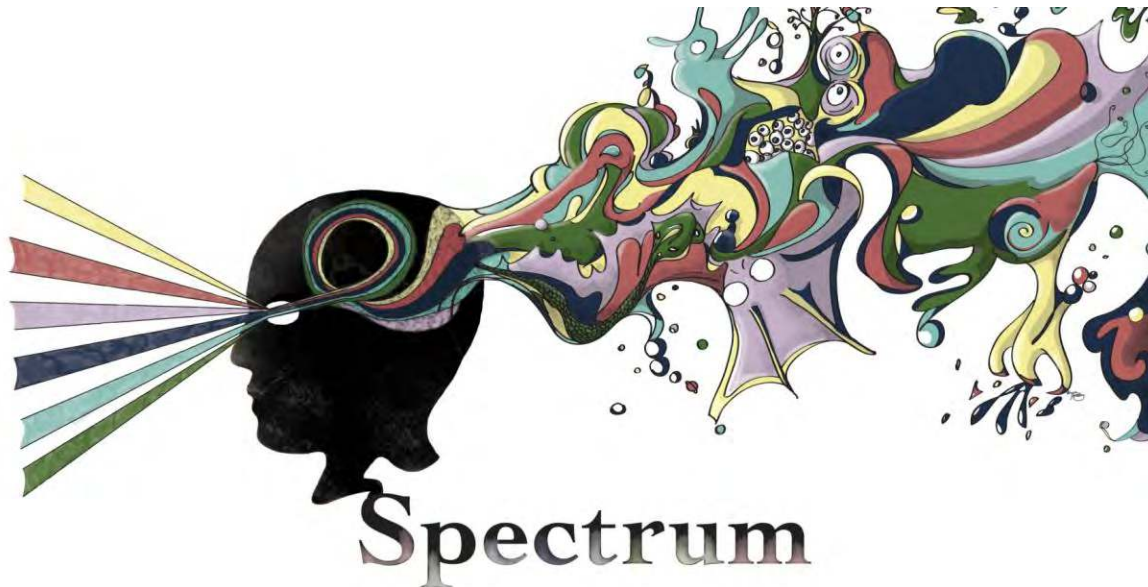


AWN's Work – Our Activities

- Current Events
 - New Fundraising Store on Zazzle
 - Supporting #CripTheVote
 - Books (2)

AWN's Work – Our Activities

- Current Events
 - **April 23rd** Event: live webcast of Panel Discussion with filmmaker of Spectrum and participants plus community events and viewing parties



AWN's Work – Our Activities

- Future Events
 - Hopefully more books
 - Expanded Regional Groups on Facebook
 - eMentoring in development
 - Crowdsourced database of diagnosticians and therapists and sensory friendly medical personnel
 - Webinars!

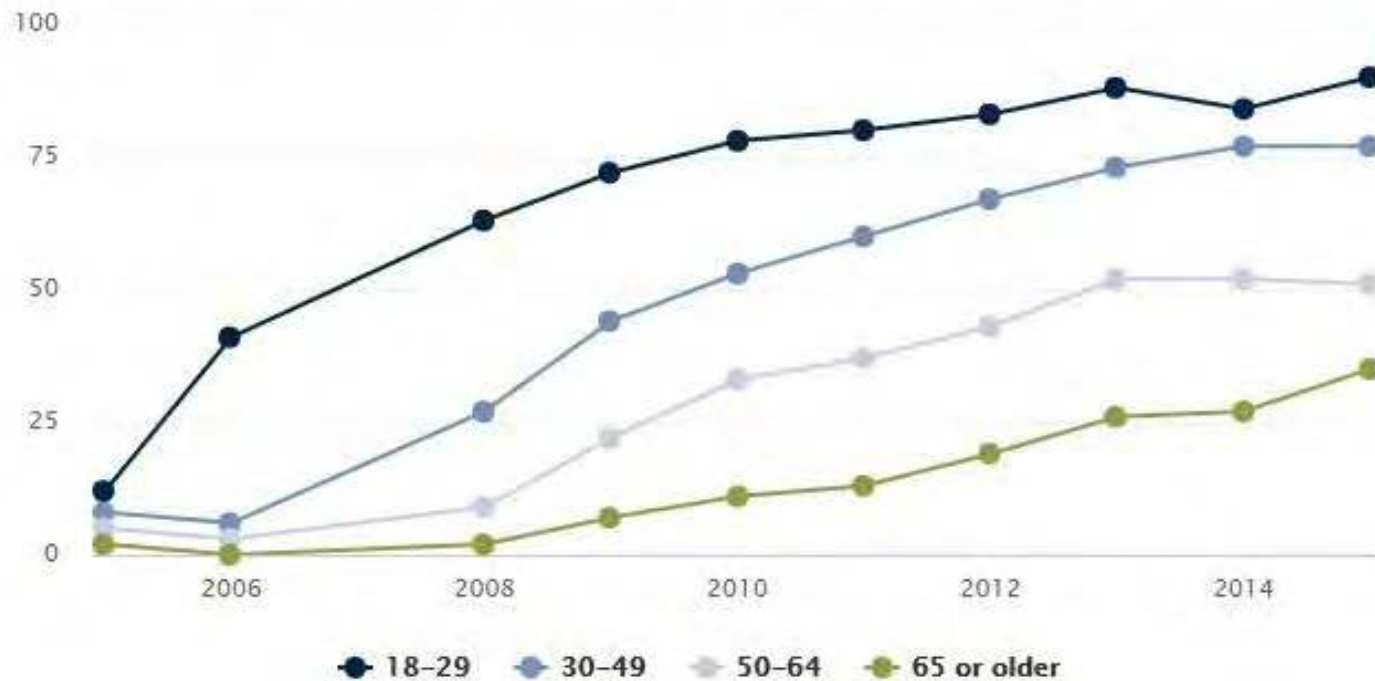
AWN's Content Strategy

- To amplify the voices of Autistic (disabled) women and other marginalized groups and to address topics relevant to them
- Within a safe space to share experiences in an understanding, diverse and inclusive environment
- **But first, some context ...**



AWN's Content Strategy – Social Media Use

Among all American adults, % who use social networking sites, by age

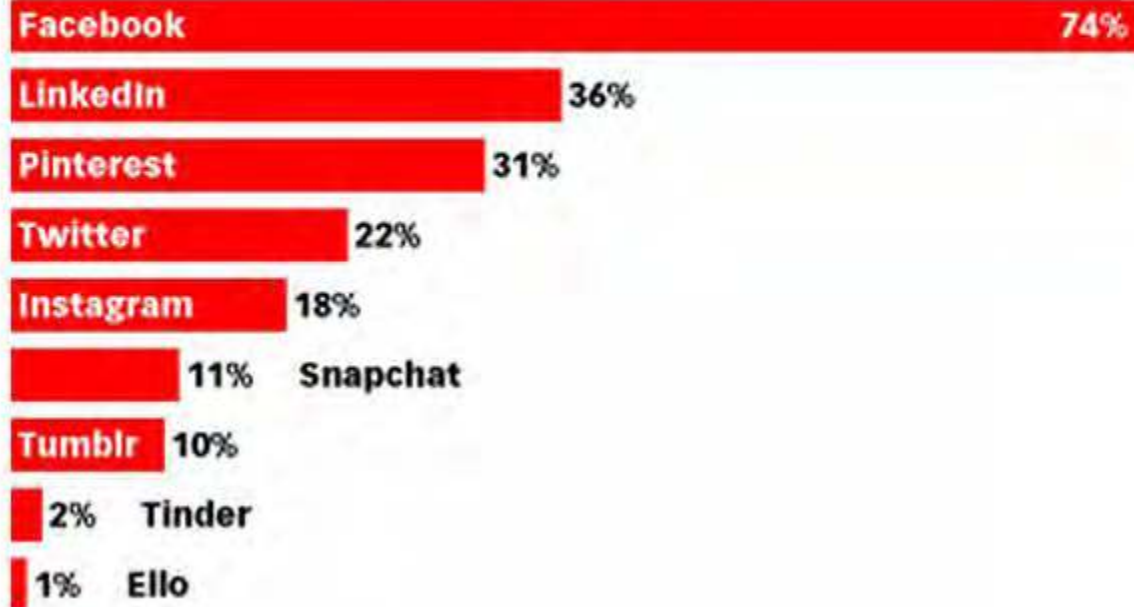


Source: Pew Research Center surveys, 2005-2006, 2008-2015. No data are available for 2007.

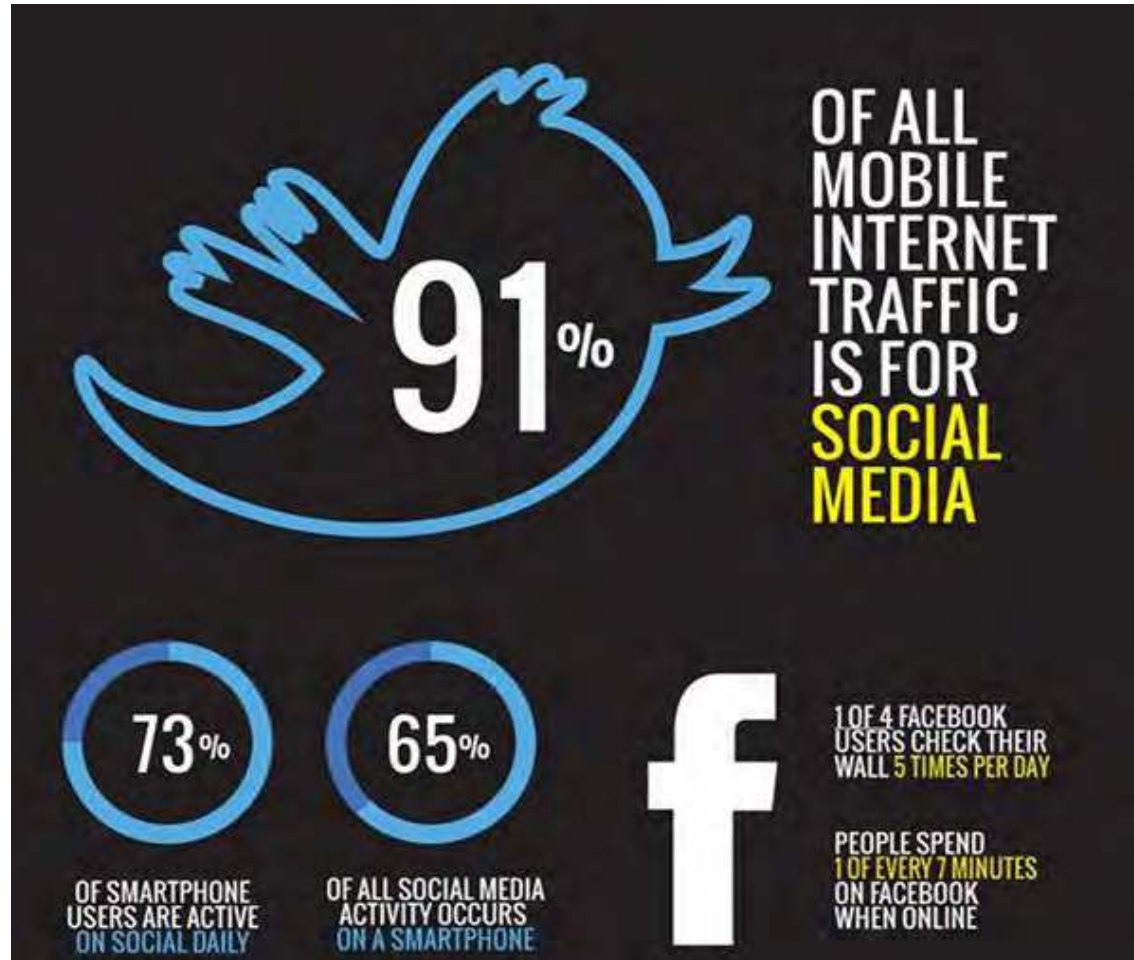
AWN's Content Strategy – Social Media Use

Social Networks Accessed by US Internet Users, Nov 2014

% of respondents



AWN's Content Strategy – Social Media Use - Mobile



Source: <http://www.nptechforgood.com/2015/09/16/20-must-know-fundraising-and-social-media-stats/>

AWN's Content Strategy – Social Media Stats - AWN

- Facebook
 - Facebook.com/AutismWomensNetwork
- As of last Sunday ...
 - Had 50,791 likes, we reached 38,580 people from February 14 – 20 and engaged 5,904.
 - Largest audience was Women 35-44 and most (64%) used mobile devices
- Twitter
 - @Autism_Women
 - As of last Sunday, 32,200 followers and had sent 28,400 tweets

AWN's Content Strategy

- To amplify the voices of Autistic (disabled) women and other marginalized groups and to address topics relevant to them
- Within a safe space to share experiences in an understanding, diverse and inclusive environment



AWN's Content Strategy

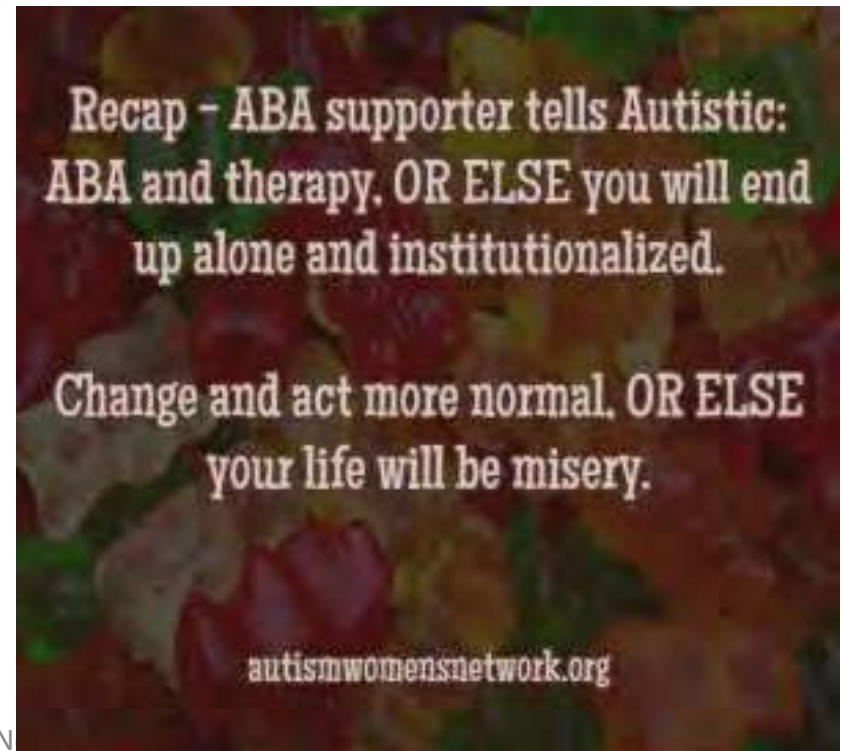
- **Recent Blog Post**

- **Have Some ABA, or Else...** Written by Amy Sequenzia on February 8, 2016

<http://ollibean.com/>



Autism Women's N



AWN's Content Strategy

- **Recent Facebook Post**
 - **Image: My Needs Aren't Special**

Image Description: Dark text reads: "My needs aren't "special". How my needs are met may be different but they are the same needs as anyone else's." Text is in circle defined by white dots on light aqua colored diagonal striped background.



AWN's Content Strategy

- Recent Facebook Post with Curated Content

The screenshot displays the Facebook interface for the Autism Women's Network (AWN) page. The top navigation bar includes the Facebook logo, the page name 'Autism Women's Network', a search bar, and links to 'Autism Women's Network', 'Home', and notification counts (241). Below the navigation bar, the page layout is divided into three main sections: a left sidebar, a central feed, and a right sidebar.

Left Sidebar: This section contains two user posts. The first post is by Tracey Walker Nukho, dated December 9, 2015, with a 5-star rating and the text: 'I will be putting together an outline for the upcoming Autistic Woman podcasts in 2016. I really want input on interest... See More'. The second post is by Erin Human, dated January 27, 2016, with a 5-star rating and the text: 'AWN is an excellent resource for support, community, and reliable info. Wonderful safe space for autistic people!'. Both posts include 'Like' and 'Comment' buttons.

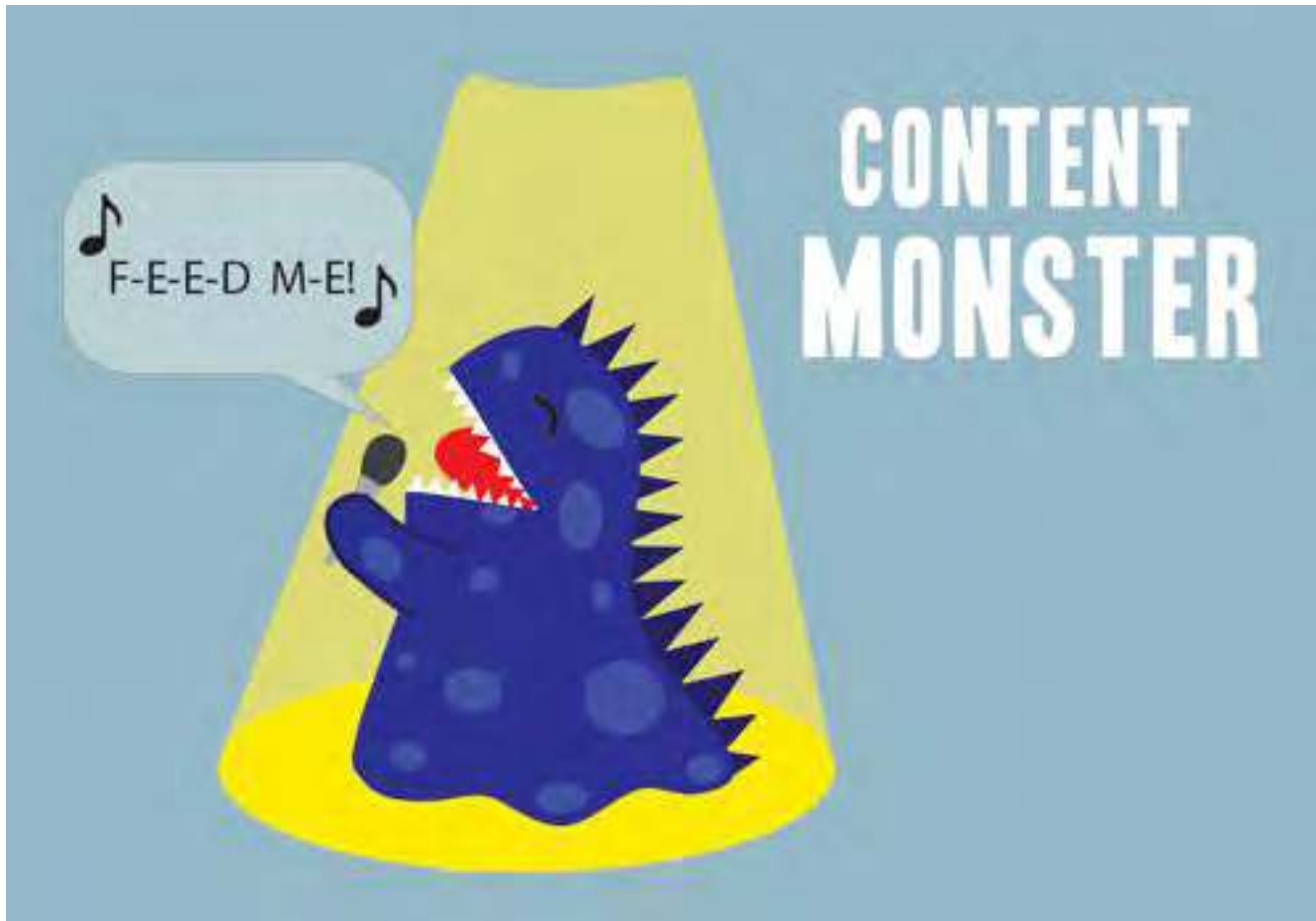
Central Feed: The main content area features a post from 'Autism Women's Network' shared a link. The post is published by Lei Wiley-Mydske on February 23 at 9:00am. The link preview shows a 2x3 grid of stylized, black-and-white illustrations of people's faces. Below the grid, the title 'What Is Face Blindness? - Science Friday' is displayed, followed by the text: 'Face blindness, or prosopagnosia, is more than just "being bad with faces."' and the source 'SCIENCEFRIDAY.COM'.

Right Sidebar: This section contains a 'Promote' button and a 'THIS WEEK' summary. The summary includes the following statistics: 329 Page Likes, 82,801 Post Reach, 5 Shop Now, 3 Website Clicks, and a 69% Response Rate.

AWN Content Strategy

- Mix of original and curated content
 - 80/20 Rule
 - Social networks are about sharing content so you need to do your part and SHARE
 - Want to cultivate networks of pages
 - Learn your tools to know what's 'working'
 - New Tool for Nonprofits: ActionSprout
 - Also from Facebook,
<https://www.facebook.com/nonprofits/>

AWN's Content Strategy



AWN's Content Strategy

- To amplify the voices of Autistic (disabled) women and other marginalized groups and to address topics relevant to them
- Within a safe space to share experiences in an understanding, diverse and inclusive environment



AWN Content Strategy

- Autistic Safe Space
 - Safe, Inclusive, Education, Intentional
 - Community Guidelines: <http://autismwomensnetwork.org/about/>
 - Autistic Safe Space – Free to Chose to be a Member
 - We ask that visitors be aware **of possible triggering language**.
 - We **do not use functioning labels** (high/low functioning autism)
 - Hate speech, hostile and abusive language will be deleted. Engaging in such behaviors will result in permanent banning from the community.
 - Enforcing Guidelines ... Moderation, Moderation, Moderation

AWN's Content Strategy – Content In Unique Places

[Zazzle.com/shopawn](https://www.zazzle.com/shopawn)



AWN new logo doggie tee

AWN's Content Strategy – Content In Unique Places



AUTISM WOMEN'S NETWORK

SHOP AWN

DONATE TO AWN

HOME

ABOUT

BLOG

CONTACT AWN

VOLUNTEER

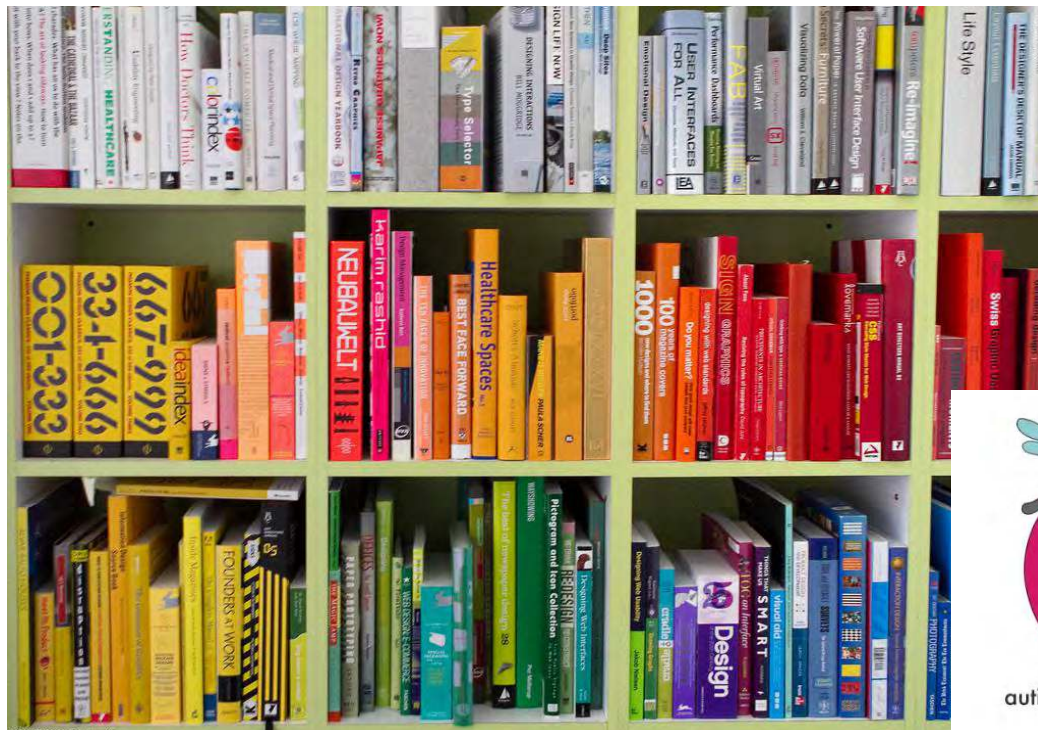
HEALTH CARE FOR AUTISTIC WOMEN

AUTISM & RACE ANTHOLOGY

Autism Women's Network Welcome Packets

AWN Upcoming Publications

- *What Every Autistic Girl Wishes Her Parents Knew*



AWN Upcoming Publications

- *What Every Autistic Girl Wishes Her Parents Knew*
 - Idea of AWN Executive Director, Sharon as a way to reach parents, who frequently contact AWN for advice; concept to frame the advice as coming from their daughters
 - 20 contributions from all Autistic women, Preface from AWN Executive Director, Sharon, and a Forward by parent advocate, Jess Wilson and Afterword by parent advocate, Beth Ryan.

AWN Upcoming Publications

- *What Every Autistic Girl Wishes Her Parents Knew*
 - Topics Covered:
 - Finding Community
 - Gender & Sexuality
 - Acceptance
 - Neurodiversity

AWN Upcoming Publications

- *What Every Autistic Girl Wishes Her Parents Knew*
 - Features Autistic women writing with honesty and generosity about the emotional needs, sensitivity, and vibrancy of Autistic girls.

Comprised of thoughtful and practical encouragement and support for parents, compiled from the acquired wisdom and experience of Autistic women.

AWN Upcoming Publications

- *What Every Autistic Girl Wishes Her Parents Knew*
 - A few of our favorite quotes
- “She will forever be happy knowing she was loved enough that you are here fighting for and advocating for her”
- “In order to accept someone for who they are, you have to be aware of what’s going on”
- “Teach your daughter to own her body”
- “Trying to fit in has been a life-long undertaking, as much a consequence of being autistic as of being transgender”

AWN Upcoming Publications

- *What Every Autistic Girl Wishes Her Parents Knew*
 - Editing has been complete and book is being prepared for publication
 - Applying for grants; slated for publication November 1, 2016

AWN Upcoming Publications

- **All the Weight of Our Dreams: On Living Racialized Autism**

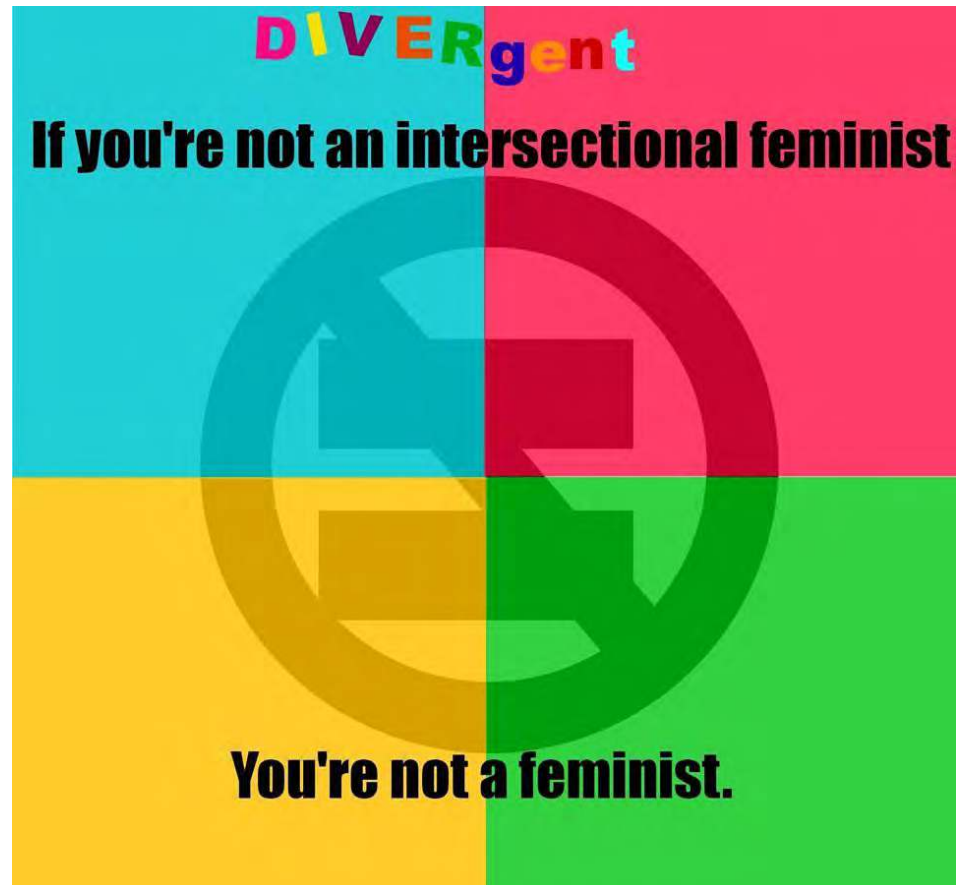
— Lydia Brown

 (“Autistic Hoya”),
Senior Editor



DIVERgent

- DIVERgent:
When
Disability and
Feminism
Collide



Our Mission

- DIVERgent works to change how disabled women are commonly perceived within society while challenging the myths of our inferiority, both as women and as disabled people.
- We explore the interactions between sexism and ableism within both disabled and nondisabled communities.
- We seek to offer perspectives on gender and disability by emphasizing non-traditional femininity and non-traditional feminism.
- We're run entirely by disabled women of varying identities and impairments.

Who are we?

- Sharon daVanport
- HK Thomas
- Alyssa Hillary
- Kassiane Alexandra S.
- Staci Forrest
- Melanie Yergeau
- Cara Liebowitz
- Kit Mead as social media manager for both AWN and DIVERgent



What does feminism have to do with disability?

- Large numbers of disabled women who are more likely to be abused, raped, etc.
- Fighting against objectification in different ways
- Growing concern about feminism not being intersectional
- Intersectional feminism means caring about tearing down all forms of oppression, including sexism, racism, ableism, cissexism, etc.



What are we doing?

Several projects on the table right now:

- DIVERgent anthology, possibly in conjunction with Autonomous Press
- DIVERgent conference on disability and feminism
- Interview series on DIVERgent social media
- What would YOU like to see?



DIVERgent Social Media

- **Facebook:**
<https://www.facebook.com/DIVERgentFeminism/>
- **Tumblr:**
<http://divergentfem.tumblr.com/>
- We're always looking for new, fresh content!



Questions?

DIVERgent: when disability & feminism collide

- Feel free to contact me at caraliebowitz@gmail.com and <http://www.thatcrazycrippledchick.com>
- Business cards available upon request



Questions?

autismwomensnetwork.org

Facebook.com/AutismWomensNetwork

Twitter: @Autism_Women

Autisticwomen.tumblr.com

DIVERgent

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[https://www.facebook.com/
DIVERgentFeminism/](https://www.facebook.com/DIVERgentFeminism/)

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<http://divergentfem.tumblr.com/>

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Lydia Brown, Member, Board of Directors

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