
TALKING THE TALK ABOUT AUTISM: TELLING YOUR STORY AND NAVIGATING DISCLOSURE SITUATIONS

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- Author, artist, advocate – and I’m autistic
 - Diagnosed at age 3 and originally nonspeaking
- Florida’s **first openly autistic attorney**
 - J.D., University of Miami School of Law
 - Practiced in healthcare and international law
- Author of **five books** about autism, neurodiversity, and disability
- Frequent disability rights commentator
- Advocate for disability inclusion and accessibility



ACCESSIBILITY NOTES

I strive to be as **inclusive** as possible!

No one person can grant or gatekeep access. Access is something we **create together**.

If you need to take a break, stand up, twiddle your fingers, fidget, or feel overwhelmed – **go for it!**

If you would like a copy of these slides, the images have **alt text** and should be **screen reader accessible** too. 😊

WHAT'S THE DEAL WITH DISCLOSURE?

Disclosure refers to a variety of **processes and tools** that a person uses to **share their disability status** with others in order to receive **support**, **accommodations**, and **acceptance**.

Autistics and allies all have different perspectives and roles to play when it comes to disclosing.

SOME GOALS OF DISCLOSURE AND STORYTELLING



IS THERE ANY POINT WHERE IT IS ACTUALLY MANDATORY?

If you need accommodations or services to be successful at work or school, **you must disclose in order to receive them.**

These processes are typically covered by the Individuals with Disabilities Education Act (IDEA) or the Americans with Disabilities Act (ADA).

EACH SITUATION IS DIFFERENT

- How (and when) to disclose looks different with different people!



PARENTS: WHO (AND WHAT) DO I SHARE ABOUT MY KID'S DISABILITY?

- Consider balancing your interests with your child's interests
- Relationship with the person
- Potential support for your child
- Purpose of sharing
- Can your child consent to sharing information?



PARENTS: WHY SHOULD I TELL MY KID?

- Creation of a **disability self-identity** and **pride**
- Self-awareness and self-esteem building
- Building **self-advocacy** skills
 - Open doors for new self-advocacy opportunities
- Your kid **already knows** they're different
- Continue building a **loving and trusting relationship** with your kids

HOW TO TALK TO YOUR KID ABOUT AUTISM

- Don't hide this information from them!
- Use **developmentally appropriate** language and concepts to explain
- Share **accurate information** and **presume competence**
- Normalize disability in your household
- Be **affirming** – you love them and nothing is “broken”
- Allow them space to be **curious** and answer their questions

ADDITIONAL TOOLS TO USE

- Media is a great way to introduce people who share your child's neurotype or disability
- People they know from your life are helpful too!



9-YEAR-OLD ME



WILLIAM
WILSON

Harry Potter

THE SELF-ADVOCATE'S DISCLOSURE ROADMAP

- Personal self-acceptance and identity
- Workplace
- Friends/family/relationships
- School



DISPARITIES IN DISCLOSURE

- **Disclosure** is a personal decision
- Why wouldn't you disclose?
 - Fear of being perceived as weak
 - Avoid perception of receiving special treatment
 - Internalized ableism
 - Preexisting stereotypes
 - Potential discrimination
 - Concerns with professionalism and licensing



SHAPING YOUR NARRATIVE

- Figure out the reasoning behind your disclosure
- How you do it might influence how others react



CONTEXT DEPENDENT: REACTIONS

- Most people (should) be supportive and accepting – or curious
- If someone is mean or unreceptive...



SHARING WITH FRIENDS AND FAMILY

- If you are late-diagnosed or suspect you are autistic, but your family doesn't know:
 - Try to use facts to back up your diagnosis or self-discovery journey
 - Ask them questions about your childhood based on your research
 - This might be different for young people or those still living at home
- Find a good time where everyone is calm to share
- Set the tone for how you want to frame the conversation
- Telling your friends or romantic partners can be ongoing
- Set boundaries around questions.
 - You don't have to know all the answers or be comfortable answering everything
- It's okay if someone else needs time to process



ADVOCACY IN THE REAL WORLD: TELLING YOUR STORY IN PUBLIC

- Lots of autistic people share their stories on social media or create neurodiversity content
- If you want to tell your story publicly...
 - Set boundaries and decide what you do and don't want out in the open
 - Tell your story on your terms, in your own voice
 - You might make some friends and build community
 - Can also develop pride in autistic identity



WORKPLACE DISCLOSURE STRATEGIES

- **Soft disclosure**

- When the person might hint at having a disability – but you might not be able to confirm or deny it
- Mentioning they are members of an allyship or affinity group
- Asking for support in a vague way

- **Hard disclosure**

- When someone precisely mentions they have a disability
- They describe it in a cover letter, resume, or other application materials
- They request an accommodation under the ADA



ENCOURAGING AUTHENTICITY

- People **feel they must disclose** when:
 - They need an accommodation under the **Americans with Disabilities Act**
 - They are unable to keep adapting and self-accommodating
 - There are breakdowns in **communication or performance**
 - There is a change in life circumstances
- Others choose to **volunteer a disclosure**:
 - They want to bring their full selves to work and take **pride in their identities**
 - They want to be proactive and limit misunderstandings
 - They view neurodiversity and/or disability as a **strength**

THE ROLE OF THE ALLY: CREATING SPACE

- **Figure out why** someone is sharing this information with you
 - Accommodation request?
 - Fun fact?
 - Spirit of transparency?
- Find out who else knows so you don't end up "outing" someone
- Listen and respond with **empathy** – it takes trust!

“How can I support you?”

SAY HELLO!



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