Autistic Women & Nonbinary Network

Information & Resources for Parents & Caregivers of Newly Diagnosed Autistic Girls

awnnetwork.org
Welcome!

Welcome to AWN Network! We are a community by and for autistic women, girls and nonbinary individuals. We strive to provide information, support and advocacy to autistic women, girls, nonbinary people, our families, friends and allies. As the parent of a newly diagnosed autistic girl, you may have many questions and concerns. What is autism? What does it mean to be autistic? Where do we go from here? How can I best support and help the autistic girl in my life? To help answer these questions, we looked for answers from the real experts: autistic adults. We have also reached out to experienced parents for their first hand knowledge, insight and wisdom in helping you to understand what can be a confusing time. It can be difficult to navigate the amount of often conflicting information available on autism today. At AWN Network, we respect and affirm the value of autistic lives. We believe that autism and disability are natural variations of the human experience. In doing so, we seek to support, accommodate and respect autistic individuals through the ideals of neurodiversity and pride in our autistic identities. We welcome all who uphold our mission and hope that you are able to benefit from the support of our wonderful community!

"After years of believing I was just as positive and accepting a parent as I could be, I stumbled upon AWN and blogs by autistic adults, and realized, I still had a lot of work to do, with fixing my own perceptions and now trying to forward the messages of autistic self advocacy. One day, my little girl will be an autistic woman, and it is my job to guide her there. This is where this organization comes in, because I had NO idea how to do it. I have no personal living as autistic knowledge. I want to be the best parent I can be, because I want her and her sister to be the best women they can become no matter what their neurodiversities are."

-Dawn
1. Relax. Don't freak out...your daughter will be okay, and so will you. She is the same child she was before you knew she was autistic. She needs you not to view her as defective or broken, because a large portion of the world will be seeing her that way.

2. It's possible that much of what you will read/see about autism may not apply. There's already great variability on the spectrum as is, and layered on top of that, the way females present is often different than the way people expect autism to be manifested. This may cause her to be ineligible for certain services as she may be perceived as not in need of them. Or her autistic tendencies may be missed, misinterpreted, minimized, disregarded, or a combination of some or all of those.

3. It might be a lonely road for her and for you. I've gone to "autism play dates" where she is surrounded by a sea of boys. She was in a therapy program where for nearly a year she was the only girl. And a lot of literature, research, and even anecdotal material one might come across is very heavily male-skewed.

4. You might have to "unlearn" nearly everything you know about autism because a lot of it is likely very biased and comes from a deficit-based perspective.

5. The way many people raise their daughters may not be the best way for you to raise yours. In order to be the parent that she needs, there are likely going to be some things that you have to leave by the wayside, and others that you might have to embrace. For example, if she has major sensory issues with hair, the whole "pigtails and barrettes" thing may not be for her. And that's okay. You can still be a "girl" without all of that stuff.

6. PROTECT HER. The rate of sexual and physical abuse that females with disabilities encounter is astounding. Furthermore, there might be characteristics that she has as an autistic female that may unfortunately make it more challenging for her to always be able to discern when she is being taken advantage of and/or when she's at risk. You might have to be very explicit and very blunt about things. You might be uncomfortable doing that, but you would be a lot more uncomfortable if you soft-toe the hard discussions and she later experiences acquaintance rape. You will always wonder if you could have possibly helped her avoid that horrible experience if she'd been equipped with more information about warning signs, etc.

-Morénike
"Presume Competence."

- Ariane

"Your child is a gift, first and foremost. You have the opportunity before you to raise a strong, amazing woman, no matter her diagnosis. Chances are the success she finds in life will not look like you imagine it to look, but it doesn't mean it will be less fulfilling for her. Be sure to learn her strengths and work in them and ALWAYS LISTEN."

-Tara

"Do: Accept your daughter, love her, accommodate her needs, advocate for her, listen to her, teach her how to assert boundaries and respect those boundaries once asserted, encourage her passions and interests, and shut down any bullying and teasing targeted at her in your presence. Do not: demand that she look or act normal, blame her for being bullied, suggest that she could overcome [difficulty] if she "tried harder," blame her or make fun of her for her meltdowns, or discourage non-hazardous stimming. Remember the following: she's trying as hard as she can, she is more confused and baffled by allistic* people than they are of her, and meltdowns are not tantrums but rather a human reaction to stress overload."

-ischemgeek

"Don't spend your days and nights worrying so much, because you will miss the joy of watching your child grow."

-Kimberly

"Supporting my daughter's needs was paramount to helping her be happy and to healing the fear in our family. Knowing more about how her brain worked solved many mysteries for us. The daily details of this include lots of sensory activities, respecting specific daily routines, respecting her need to pull back when overwhelmed, and not getting angry when she's overwhelmed and melting down."

-Kathryn

*"Allistic" refers to anyone who is not on the Autistic spectrum
What is autism?

Autism is a pervasive developmental disability that impacts communication, movement and sensory processing. "Pervasive" means that autism affects every part of the person because it is their neurology. Autistic people are as diverse as any other group of people with their own strengths and weaknesses.

The amount of support that each autistic person needs can vary greatly between individuals and even in the same person from day to day. However, each and every autistic person experiences and interprets the world around them in distinctly autistic ways.

The best way to learn about autism is to ask an autistic person! Autistic people are the only true experts on autism!

"Autism is deep love. People write it off as special interest or obsession, but even if it's not something I can excel at, I can excel at loving what I love, loving what I do, loving who I love. Autism is being able to be consumed by love and interest, it is giving 100% because it is an insult to the thing one loves to give any less. Autism is going big or going home."

-Kassiane
What is acceptance?

"It means not changing what fundamentally makes my child who she is. It means respecting her stims, it means respecting her sensory needs, it means presuming that my child is as competent as the next. It means giving her the space and accommodations to succeed with her unique neurology."

-Sandy

"That one's autism diagnosis should be viewed in the same manner as other core characteristics of that individual--as part of who they are, and as such something to be celebrated. Just as someone might be proud of being Latina, or proud of being a woman, etc, they should identify with and be comfortable with who they are. And Autistic is who they are--along with all of the other components of their personhood. Autism acceptance is critical."

-Morénike

Image: blue/green background with hearts and a star: "Fear is the enemy. Hope is everything. Acceptance is how it happens. - Lynne Soraya, What Every Autistic Girl Wishes Her Parents Knew autisticsgirls.com"
"I'd ask parents and caregivers to recognize that she does NOT have to change or hide who she is in order to find someplace where she fits in or can be accepted in the world. The world is big. We do not live in a monoculture. Autistic girls learn and gain skills and develop relationships differently from most people, not in a way that's inherently defective or insufficient. It's not wrong that the way she works is very different from most other people. People find all different ways of living in the world."

-Emily

"Changing the world for my daughter and not her for the world."

-Ginger

"Acceptance means not trying to change who I am."

-Terri

"If you want your daughter to learn to love herself for the amazing person that she is, then you must learn to accept that she is Autistic, and she is exactly who she was meant to be."

-Lei
"People will tell you "she's still the same child she was before the label" and that is true. You already know your child -- the label is confirmation, not change. People will also tell you that she is not defined by her autism, that it is something outside of who she is and that she can overcome it. This is not completely true. Autism is pervasive -- that is to say, there is no "place" inside your daughter that is the not-Autistic place. She is not defined by her autism, yes -- she is many, many things and will become many, many things through the years and autism is only one of those things. However, autism is big and you cannot ignore it away or define it away or trick it into going away by not using the words about it.

**Autism is the way your daughter's brain is put together.**

If you believe in a marvelous God, then you must believe there is a purpose for the unusual and beautiful way your daughter's brain was made. If you do not believe in God, then you must come to accept that nature has mysterious ways and has produced this wonderful and beautiful daughter of yours that you are tasked to love and accept the way she was born.

You cannot peel away the autism. You cannot discipline it away, drug it away, cut it away with surgery. It is an indelible part of who your daughter is and your job as parent, grandparent, caregiver, person who loves this child ... your job is to help her grow up to be the best Autistic person she can be. She may speak; she may never speak. She may drive a car; driving may be beyond her abilities. She may marry, raise children, live in the suburbs with a dog and a cat. She may live her life alone and happy to be that way.

You cannot predict the adult she will be by looking at the child she is -- this is true of all girls, but infinitely more so with your Autistic girl. We are still learning about autism across the life-span but one thing we do know is that Autistic girls who might appear nearly identical at age six turn out to be completely different at age twenty-six.
So focus on who you have in front of you right now and don't let fear lead you down paths that damage your beautiful girl for the uncertain promise of a future outcome.

Talk to other parents of Autistic girls. Talk to grown Autistic women. Learn as much as you can directly from people living it and filter the words of "experts" through the sieve of lived experiences. Finally, if you still feel tempted to try to remove your daughter's autism as if she were an apple and you could wield a corer, skillfully dissecting and discarding everything you deem not-normal about her, I would like you to read a short story by Nathaniel Hawthorne, "The Birth-Mark." Read it and reflect on what it might mean for you as the caretaker of an Autistic child."

-Maxfield
"Parents who practice acceptance will not allow anyone to devalue their children. They will not allow anyone to value their children on the basis of what they can do, but on the basis of their humanity."

-Amy Sequenzia
Autism Acceptance-It Requires Action
Thank You For Being A Part of Our Community!

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AWN Initiatives

Divergent: when disability & feminism collide

Committee on Autism & Ethnicity & Autistic POC Fund

Health Care Provider Database

AWN Publications

What Every Autistic Girl Wishes Her Parents Knew

All the Weight Of Our Dreams: On Living Racialized Autism

Volunteer Opportunities

Donate To Awn Network