To Tell or Not to Tell - Why It Shouldn’t Be a Question?
A Common Debate Surrounding An Autism Diagnosis

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I stand among my teammates before practice begins as they talk freely about other humans, movies they want to see, plans they have made, things that happened in the cafeteria or in one of their classes. I can gauge the general topics and themes, but it all moves so fast. I know that in a group conversation, the members of the group are all supposed to contribute—and all the others do. They do so with enthusiasm and ease as I chase an elusive ball of garbled, jumbled words and sounds as it ricochets between them. I hear and comprehend the words, “song,” and “radio,” and I access my minds intricate web of lyrics and factual information about music, bands, singers... I don’t really have a favorite song, there are so many. I have favorite songs for various activities and occasions and I have songs I prefer for certain aspects of instrumentation and songs I prefer for the vocal range and songs I prefer for dancing versus before a game. Some songs sound better from speakers than they do in headphones and vice versa. This fact strikes me! A rush of energy from within as I feel I have something truly fun and fascinating to contribute, but when I surface from this world of thought, the words I comprehend are “mall,” “new store,” and “weekend.” The moment has long passed.

Later, I am in the shower after practice. My words are unlimited and flowing and it is as if I am giving a lecture on many of the topics to which I could not contribute earlier. Millions of connections fire in my mind. The thoughts I am able to produce are abundant and brilliant. Next time, I think, next time I will be able to speak of these things in the group conversation. I will be able to say them out loud and it won’t be too late. Next time comes and goes over and over and the pattern repeats. I notice that the pattern is not just in group conversations, but one-on-one, in the classroom when attempting to take in information and produce answers to questions. I wonder why I am not capable and how all the others are. I give up—it is far more enjoyable to be on my own and away from the madness of conversation. I am quite content to be on my own.

Flash forward 25 years: I sit among my co-workers before a meeting as they talk freely about other humans, movies they want to see, plans they have made, things that happened over the weekend, or in one of their other meetings. I can gauge the general topics and themes, but it all moves so fast, and it acts as relentless noise in an environment that has already been wearing me down all day... all week... really since beginning this job just two weeks ago. Energy swells inside of me and rises rapidly. I feel as though I could flip the table. The world is closing in around me as my vision and the sounds all begin to blur.
I don’t know how I am able to drive home and when I get through the door, I have just barely made it... again. I am drained and exhausted, yet practically bursting with negative pent up energy. I hear the bass line of my neighbor’s TV pulsing through the wall, and simultaneously, I feel the energy trying to erupt. I run upstairs into the bathroom and turn on the fan. I can still hear it. I run out of the bathroom in a blur with walls caving in on both sides and not fully able to see clearly.

It’s over. I breathe heavy. I am fully aware again. The energy has been released and only fatigue and confusion remains. I look at the hole in my door. I can still feel that my leg had been in motion and I can feel a soft hum in my foot. After a moment, I realize that I have kicked through my door. Just as I had thrown my phone through my wall earlier in the week, and ripped apart a bedside table on another day, and broken the console in my car on a day I did not make it inside, and smashed a cabinet door into pieces. I sit down on my bed. I am exhausted but my eyes are so wide they won’t even blink. I am confused. I am lost. I don’t understand what’s wrong with me. I don’t understand why others can do things so easily and I cannot. I feel as though the best part of my life must be over and this is all that is left and I ask myself, am I depressed? Am I suicidal? I ponder it very seriously. I know, though, that I don’t want to die... yet I cannot figure out how to live in the world as it is.

I feel incompetent, less than, I am incapable. I feel I must be a failure ill-suited for this world. I feel I am inadequate and that something must be wrong with me. I feel I am a problem and that I am dangerous and destructive. I feel useless and broken. I hide under my blankets with all the shades drawn. It takes no time to fall asleep with this level of fatigue and drain, and I sleep for 26 straight hours... for the third time this week. Yet when I wake up, I am not refreshed or renewed, I am hopeless and I am tired again just thinking about this reality for the remainder of my life.

Later, I am in the shower before work. My words are unlimited and flowing and it is as if I am giving a lecture on many of the topics to which I cannot adequately contribute and may have to endure today. Millions of connections fire in my mind. The thoughts I am able to produce are abundant and quite brilliant, given that I have no interest in the topics nor any understanding as to why they are topics being discussed.

This time, I think, this time I will be able to speak of these things in the group conversation. I will be able to say them out loud and it won’t be too late. I’ll be able to just be in those moments calmly like the others in the room. This time comes and goes over and over. With far too much energy, I am able to say words that align with the bombardment of words flying around the room. I am never able to do it naturally or calmly or enjoy it and I barely make it out of the room and home before I rip my scalp with my nails, break things, throw myself into the concrete floor and/or collapse into a very long sleep.
The pattern repeats. I wonder why I am not capable, why I can do my job with ease even when it takes hours, but why I cannot do these unstructured chit-chats and how all the others are quite adept. I want to give up because I cannot live like this – I am not cut out for this. I am deficient. Something is wrong with me, and something has always been wrong with me. I can’t do it – any of it and I don’t know what to do about the fact that I am unable to navigate this. I don’t know how to make myself sit calmly and authentically laugh and talk about nothing with other humans. I must be broken. My thoughts are only further confirmed when others around me say things like, “that’s just life,” “that’s just the way it is,” and “nobody likes meetings.”

Flash forward to now: I was never broken, but I truly did not fit my environment. I am autistic. My brain is different. My regulation needs are different. I am not deficient; the world is ill-equipped to meet my needs naturally. I was not suicidal, but I could not figure out how to live...until I figured out that I am autistic. This changed everything including the way I viewed my entire past and present. This was the difference between believing I was an unfit and problematic creature never meant to exist in this world to knowing that I must change the world around me to survive and thrive. ‘Autistic’ was the difference between bending, breaking, snapping and shattering every single day; doing everything I could to put myself back together as the world would like me to be and hiding any of the cracks that were left and understanding, healing and growing into me. ‘Autistic’ is the difference between being employed and unemployed. It is the difference between deteriorating mental and physical health and the peace that comes with knowing the true me. ‘Autistic’ is the difference between lost and found; between utter confusion and the self-awareness that is the foundation of being able to advocate for one’s needs. It is the difference between living each day just to be able to make it home before one falls apart and knowing that one will fall apart at times, but that there are so many things that can be done to protect oneself from experiencing it daily and with such intensity and duration. ‘Autistic’ is the difference between “I am not good enough,” and “I deserve better than this;” between “I don’t know what to do,” and “I know exactly what I need.”

‘Autistic’ is the most important thing I have ever learned about myself. It did not hurt or harm me to learn this. It empowered me and set me free. It comes with challenges, of course, but it has been integral to my success. The challenges are very real and they do not go away with having a diagnosis, but they are known and understood and therefore, I have the opportunity to prepare, fight, use tools, strategies and work within my strengths. ‘Autistic’ is about my brain, therefore it influences every aspect of my life at all times. To not know this identity is to not know myself, and to not know this difference, is to unfairly assign myself deficits. It is to believe I must endure a world that was designed by and for people with brains unlike my own in the ways that they deem acceptable.

To not know myself as Autistic is to not know myself at all. To not know myself at all is to not know myself in relation the world and humans that surround me. To assume I can function without this knowledge... it is an impossible ask and I will surely fail. I have watched myself fail without this knowledge and I refuse to let it be the fate of others.
**Mother of 7-year-old autistic child- 7/2020**

reflecting on her child’s autism diagnosis

Why disclose?

It never really crossed my mind not to, honestly. Why keep that kind of free-ing information from you? It’s the difference between feeling like there is something wrong with you, and understanding that you simply experience the world differently. And that you’re not alone in that.

A fair amount of our communication is non verbal, but you freely express the importance of owning your true self.

You feel your joy (and also your pain, and everything in between) with your entire being. Stimming. Not only is it ok, but an integral part of your self regulation. You’re free to read your body signals and react accordingly through requests and actions - squeezes and jumping and swinging. And exploring outside - which is a part of our daily flow. I see your whole body relax in this environment. Nature is your best regulator.

The importance of all this - what you know to be true - is the fact that in life you can do most things... but environment and certain adaptations are essential. Understanding your brain, your sensory needs, and how to regulate and adapt to any given environment is absolutely necessary - to both be your true, authentic, self and to survive in a world that doesn’t always seemed to be designed for you.

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**Shadia Hannock- 7/2020**

Autistic Self Advocate, diagnosed at 3 years old

(1 of 2)

*Do not tell perpetuates:*

- There is something wrong with saying 'Autistic'
- Autistic individuals often being aware they are different but viewing difference in a deficit based lens
- No explanation as to why the Autistic person is different and feels different|Isolation - the Autistic person may wonder if there is anyone else like them

Often people who support 'do not tell' are against 'labels
**Telling Promotes and Supports:**

- **Authenticity.** My mother always listened to #ActuallyAutistic perspectives and searched for the viewpoints of Autistic adults to inform how she approached my upbringing. I worked out my diagnosis at the age of eight years. I remember seeing a poster at my primary school – all I remember is seeing the word ‘Autism’ – and I thought that it described my friends well (I was part of a program for Autistic and Neurodivergent students at school, so many of my friends were Neurodivergent). I asked my mother whether my friends were Autistic, and then connected the fact that I must be Autistic. My mother responded authentically and honestly, and told me that my friends and I were indeed Autistic. Particularly in high school, where I began to experience bullying and discrimination and started to become aware of being different, it was vital to have my mother as a support network. She helped me in fostering a positive Autistic identity by having open conversations about differences, my self esteem, and directed me to valuable resources such as autobiographies about Autistic adults and their experiences. I believe had I not had this honest open communication and awareness about my difference, I would have been stuck in a deficits based viewpoint of my neurology.

- **Access to a community.** Knowledge of my diagnosis helped me to connect with and relate to fellow Autistics. As I began to foster a positive Autistic identity, I began to find more likeminded people, particularly Autistic and Neurodivergent individuals. This also helped me in learning more about Autism, and the diversity it brings. It helped me feel less alone, and showed me that there was a community I belonged to.

- **Autism describes how our brain works and reassures us that it is not wrong and there are others like us.** Whilst every Autistic person is different, we often share some similar experiences. It is wonderful to have other people to support each other and help with educating the community about being Autistic. Before finding Autistic individuals like myself, in high school I questioned my diagnosis and whether I was indeed Autistic. I felt invalidated when often well meaning people said I didn’t seem Autistic, or that I must be high functioning. With access to my community and hearing the viewpoints of Autistic advocates, I was reassured that my experience was valid and that I should have confidence in how I view myself.

- **Idea of Neurodiversity:** Diverse minds are crucial for progress in society. When disclosing, it is vital to introduce Autistic individuals to a strengths based approach and direct us to viewpoints that views Autism as a difference, as opposed to a deficit or disorder. Before finding Autistic individuals that were proud of being Autistic, I thought that being Autistic was a weakness, something to be ashamed of, and I had low self esteem. When I discovered the Neurodiversity paradigm, it completely shifted how I viewed myself and others with differences and disabilities. Furthermore, realising that everyone is different and experiences their own strengths and challenges was incredibly affirming. There are challenges I face that others do not, however there are also skills I possess that others do not as well!
Rose - 7/2020
11-year-old autistic girl, Content Creator - YouTube channel “The Secret Life of Rose”

Thoughts Rose shared in conversation with her mother about her autistic identity:

It’s definitely better now I know I am autistic, I have always felt I was different from my friends.

Now I know and others know I am autistic it means I can do things without getting told off, like when I hid under the table in the restaurant as it was too busy and noisy and you left me there.

Rose’s Mum’s Perspective:

Since Rose has had her identification she has unmasked more, which we are pleased about. We have noticed her stim more openly at home and be braver about accessing adjustments in school to ease her anxieties. We have been able to talk more openly about the challenges bought about by the outside world and how we can avoid, manage or overcome them.

We noticed in Rose that after identification she sometimes appears to seem more autistic.... Rose is much flappier and jumpier (stimmy) than she has been before.

I think this is great... I think it means she is showing and accepting her true self.

J. - 7/2020
professional woman and mother, diagnosed in adulthood

I was diagnosed age 37 as a result of having my child identified as autistic and knowing I’m just like them!

I haven’t told people, I’m scared of their reaction and them saying I’m neurotic and not believing that I am autistic! I mask in front of many people. They don’t know the real me. When I am with people I feel like I am being disloyal or hiding something from them, and; it makes me feel uncomfortable on top of the masking. I desperately want to tell people but they don’t know or understand what autism is and I’m too fearful of their reactions.

In my work I always advocate that children are told about their identity.
Patti Menzel - 7/2020
Autistic woman, diagnosed autistic at 49
(despite starting in special education at age 5)

Learning my Autistic identity has been transformative and empowering! Initially, my response was colored by common misunderstandings and ableism, but the opportunity to find my Tribe and realize a balanced, informed-from-the-inside perspective on autism gave me an awesome sense of positive healthy self identity. Authenticity felt correct, genuine, honest, and true. I recognized that tremendous gifts and challenges don’t cancel each other out. Having a healthy, positive self identity came from switching out old false labels (lazy, dull, aloof) with an identity that instead meant I was a detail-oriented, passionate, pattern recognition expert. Seeing similar strengths in others on the spectrum soon became such a rush! Finally having an answer for the “Why?” of tougher stuff like elopement, meltdowns, SIBs, bolting, and major bloopers of self-care made them feel a great deal less strange, and much more understandable. That’s when empowering myself really began, because while my neurology is too reactive to stop most of these once started, I’m now happily able to look at situations and choose a strategy or support to coast through easier, and when not, I am able to decide which situations I simply avoid altogether. Not all environments are for all people. Disability is simply a part of the normal human continuum. Difference is the one thing we all have in common.

As children, how those closest to us feel about our autism impacts us greatly. Parents have a wonderful opportunity to build a strong positive, healthy self image in their Autistic child. This is possible by consulting Autistic adults who can represent the many different ways we live happy, successful lives. Autistic success and happiness may indeed often look different than neurotypical versions of such, so the trajectory will differ, too. We don’t fit in, instead, we belong. We choose our circles. Those who appreciate our strengths value us for who we are. Having the right identity brings pride and a positive sense of authenticity.

When someone hides our diagnosis, we’re now made responsible for their anxiety about who we really are. It’s a colossal burden to feel one must walk on eggshells to avoid frightening people with the truth of who we are, all because their views on disability and difference need to evolve. Ableism is a painful place, but societies are not static, they continue to develop, and so can anyone. Supporting neurotypical parents of newly diagnosed Autistic kids must involve lots of mentoring from Ausome adults, sharing all the amazing, positive ways Autistic success and happiness can be. The highest form of inclusion is representation. The autism industry needs Autistic adult mentors for neurotypical parents and professionals. Seeing “difference” in a position of influence can encourage society to bring perspectives on disability to a more positive place. Autism, it’s an identity as much as a diagnosis. We need to know who we are in an honest, balanced way, so we can grow a positive, healthy, happy Autistic identity. Rock on! 😊
Disclosure of information to the individual about their own brain and identity should never be in question.

Humans are constantly developing their self-identity, it’s an important aspect in the understanding of self and how others perceive us. Through identity we project ourselves to others; different aspects of the things that make up who we are create that identity. Neurology is the biggest driver of our identities, for all of us. Neurology describes how we process information, how we move, how we think, how we feel and how we communicate;

For any person, how they are given knowledge about themselves frames how they will continue to view that information; it’s the platform upon which they will build their knowledge. If it is given to them in any kind of negative way the child will forever associate negativity with it.

Helping someone understand that their brain and body work differently in comparison to others and that many of the issues they’ve had in their life is not because part of them doesn’t work properly is critical to building a positive self-identity.

So, it’s how you define it which is important;

Negatively, which centres the fault with the individual:

Your life is hard because of Autism

Or, positively, which centres the fault outside of the person:

Your life is mostly hard because of how the world perceives you because you are Autistic

Equally important is that disclosure of an Autism diagnosis happens as early as possible and is delivered as positively and productively as possible.

A parent initially withholding information related to an Autism diagnosis and then revealing it later to their child (often too late), can create enormous trust issues between the individual and their parent. Information willfully concealed perpetuates shame and stigma. Honesty breeds strong relationships. Exploring understanding together can create unity and improves self-belief and trust in relationships.
Much of the reticence to share diagnosis, from a parental point of view is a projection of our fears.

Fear for our children’s futures, fear of uncertainty, fear of difference. This fear is a reflection of how we are conditioned by society to extrapolate our perfect children’s perfect lives and our perfect understanding and relationships with them.

What is needed is not trying to normalise disabled people through therapies so that they aren’t different any more, but the normalisation of disability in society and the professional world, so that people’s individual needs are accepted and are met individually. That what makes a person who they are is absolutely valid and ok and should be celebrated.

For additional insights related to these thought provoking autistic perspectives, please visit:

Kieran Rose- https://theautisticadvocate.com

Rose- https://www.youtube.com/channel/UCRsFBiaBmp3V0efxlBo-3wA

Shadia Hannock- https://www.autismactually.com.au/?fbclid=IwAR0pWf33fg47Ekek8EEu8InSUGjpl29chKs6OM6P8fOy

Jacquelyn Fede- www.autismlevelup.com

itcannotbecontained.com
DO TELL THE INDIVIDUAL
By engaging with and listening to members of the community, we’ve established that disclosing a person’s autism diagnosis to the individual should NOT be the subject of this debate. Telling the person about their diagnosis is the first step to supporting a positive, authentic, autistic identity and to helping the person understand their strengths, needs, challenges and also the type of supports from which they might benefit. In addition, this understanding can be used to help create relationships and environments that are safe, comfortable, and supportive.

It is critical to acknowledge that while a person’s neurology, learning style, and identity should never be withheld from them. However, there are times that a person may choose to not disclose these things to others.

DISCLOSURE TO OTHERS
Many factors may influence the autistic individual’s decision to disclose their autism diagnosis to others. These may include the current, predominant cultural perception of disability, lack of understanding of autism by others, concerns for safety, prevalence of prejudice, evidence of discrimination, and/or fear of stigma, among many other factors.

It is vitally important to state that these decisions are real and difficult. The need for such decisions should not be a burden for autistic people, but it is the result of the current state of our society and the work that must be done!

LEVELING UP!
We all must continue our work to support awareness, acceptance, appreciation and empowerment through advocacy until autistic individuals no longer need to decide whether it is safe and beneficial to disclose their identity to others. We must create a world where individuals can be openly autistic and one in which they can access supports as needed without stigma, fear or backlash.