

Episode 8: Avoiding Harm for the Holidays

Hello as always, and welcome back to another episode of Actually Autistic Educator. We'll be back next month to continue the second half of our neurodiversity topic. Because between Twitter, Facebook, and Reddit I saw so, so many posts from or about autistics and issues around holidays this week that I thought it would be good to do a special episode to cover a bit about some things I and other autistics wish people understood about how the holidays may impact us, especially from when we were kids.

As always transcripts are on my Twitter and Facebook and linked in the show notes. Also seriously thank you to the people who left me messages after last episode! I got three lovely ones that made me tear up a bit, and this episode was partially inspired by a very sweet request from a non-autistic parent about ways to better support their autistic child, which...I can't describe how wonderful it is to see that perspective. So many parents treat their autistic child ... really poorly or make it all about their preferences and wants rather than the wellbeing of the child - for parents out there listening looking for ways to make your autistic kids happier and less traumatized, thank you. And to everyone, if there is a topic you think I should cover, a question you want to ask, or anything you'd like me to know, contact me through my Twitter or Facebook at Actually Autistic Educator, or you can leave a voice message through Anchor.

This episode is using quotes from a poll I took on social media about things autistics wish people had known regarding holidays when they were children, disclaimer, the responses were mostly people who celebrate Christmas and that was the major holiday where I grew up, with some other responders who celebrate Hanukkah, Kwanza, and Yule, which is not remotely a universal mix, so not everything I am going to say will fit every holiday and some parts (gifts and lights mostly) are clearly more about Christmas

which was why I didn't plan to do anything holiday themed for this podcast, but I think the themes we're going to talk about can be useful for anyone who has a change in their daily schedule at any point in the year for a special event, both for autistics to figure out ways to make social get-togethers less stressful for themselves, and for parents, loved ones, and other friends to learn some things they can be aware of to make an autistic's holiday a little bit better.

Holidays can be a bit of a mine field for autistics for a lot of reasons. These often involve travel or other changes to routine, an influx of social times with people you might not see a lot, traditions that involve doing many things outside your normal comfort zone, different food combined with eating socially, and more. Now some autistics may love this, others may love parts and dislike others, and others may find holidays become just a source of trauma and dread - every autistic is different, so don't jump to conclusions about a specific autistic and their needs from this, more think of how to be more inclusive and welcoming of a variety of differences - especially because autism is highly underdiagnosed as we've covered before, and other neurological differences, past family trauma, and even just introversion and extroversion or sleep deprivation might mean a lot of folks run into some of these same issues. I know we're tabling neurodiversity till next time, but this ties in - lot of folks are different in unique ways, the more welcoming and understanding we can be the better.

One of the first themes I saw from the responses I got was struggles with parties, both the noise and the sudden increase in people.

Christine Lee says, "I hated parties before I was out of elementary school because they were loud, bright, overwarm, and just sensorily overwhelming. I wasn't trying to be rude or insincere when I fumbled verbal thank yous after getting presents, I just struggle to

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think and talk and people while in sensory overload.”

This is so important - autistic sensory differences means that the atmosphere that feels bright and welcoming to one may make some folks utterly miserable, and it can impact our ability to speak and move. We sometimes talk about autism and hypo vs hyper sensitivity and in textbooks about autism I've seen it treated as a single dial - an autistic is either hyper sensitive to lights, sounds, touch and providers should ensure they have fewer sensations for all of these, or hypo sensitive and doesn't feel as much and is always looking for more sensory input and carers should provide lots of stimulation. In general I don't think that's how it actually works - from my own experience and what others have shared it's a lot more variable - maybe usually liking firm pressure touch but hating bright lights or sounds rather than all or nothing, though I also see a lot of using stronger sensory input as a way to deal with hyper-sensitivity - needing loud music to drown out hyper sensitive hearing of the two tvs going plus the refrigerator, heater, laptop, and electric lights (those are the actual things I can distinctly hear in my house as I write this), but also it can be super variable - the more input, stress, and such can make things worse, so the lace edged shirt that was ok to wear when in your own house in quiet might become scratchy and miserable when it's warmer and there are people everywhere. Light levels that normally are fine suddenly feel too bright when you're overextended from having to socialize - like how having a migraine or hangover can suddenly make normal lights and sounds feel awful.

Stephanie from Boston had several thoughts here - they started with “Turn the music down! My father loves blasting music all the time, and with that and a house full of people, it's intolerable.

Let me have the right to sit in a coat closet and read my book/play video games/do whatever the hell I want to do for half an hour without making a big deal about it.” Another friend shared “We are

overwhelmed and overstimulated, what might seem like small things may set us off and we need space. GIVE US THAT SPACE.” As someone who is still bitter about having hidden at age 11 in a closet in my bedroom behind my clothes and under a blanket in the dark to avoid a meltdown during a party and still was dragged out and mocked for being anti-social, I agree entirely.

So solutions - having options to escape is so important especially because of that variability we mentioned before where something that normally is fine becomes awful, so potentially having different spaces where folks can go that are quieter vs louder and more or less bright if you are a host is wonderful, making sure people (especially kids) are allowed to hide in a room or closet or going for a walk if they're overwhelmed, and checking in with folks in general and encouraging them to express their comfort needs. If you're autistic at any age, you are not being selfish if you need ear plugs or headphones, if you need to go for a walk or find a quiet space to breathe in - if the people you're with aren't accommodating then some stealth options are: an emergency call from work or a friend and you have to take this and go sit in your car. It's a beautiful night/day for a brisk walk! If you drive, then be the one to volunteer to get more ice or soda from the gas station. If someone doesn't acknowledge the term “sensory overload”, call it a migraine - I literally can't tell them apart sometimes, it's a very apt explanation, and people may be more understanding of your needs, especially how it can create light and noise sensitivity and trouble eating. It's also ok to have to turn down invites, only visit briefly, or insist on a hotel, even if other people try to guilt trip you. You get to decide your own boundaries and you deserve to be comfortable.

Related to this Stephanie continued, “Don't try to pack too many things into one day. We'd go to my Father's mother's house for Christmas Eve, which generally lasted until about midnight, and I'd get tired and cranky and there would be arguing, then Christmas morning at my parents house, and then

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Christmas afternoon at my Mom's mother's house, and that was always one straw too far. This is still the case except that the afternoon party became my husband's family, and I feel really guilty when I try to wiggle out of having to go because I like them but I just can't after already doing two holidays in 24 hours." Honestly that sounds hellish to me, I could love everyone involved and that would still utterly destroy my ability to function. Some autistics might be fine with this, but, especially to autistics listening - you're valid if you need to set boundaries around what you can comfortably do, be that limiting trips, visiting the weekend before or after, attending remotely - you don't have to burn yourself up to keep other people warm. Non-autistics, please remember that these boundaries are not a rejection of you, if you care about someone then let them not hurt themselves, even if it means needing to make some changes.

Touching was a big part of this too - the expectation to hug or even shake hands with others is rampant with family get-togethers and can be so uncomfortable for multiple reasons.

Jen from near Boston said "For myself, it was over stimulation via hands touching. Like many folks had sweaty or lotiony hands, and I have really dry hands naturally, so I really disliked grabbing folks sweaty hands or full of over scented lotion hands. It was like I felt it was almost abrasive to touch those hands. So I actually liked hugs better. Because it didn't involve hand touching! ... But I'll still do a fist bump any day over a hand shake. Even pre covid."

Ben Larson said in all caps, which I so agree with - "STOP MAKING ME HUG STRANGERS. Yes, they're family, but I see them once a year for fifteen minutes. That is a STRANGER."

This was probably the most frequently said thing actually. Even if kids and adults are given the choice, adults often make it clear that they will be upset if you don't "choose" to hug. I'm going to take a moment because this is a huge problem in general, especially

as a woman, the social pressure to give up control of their bodies to others is so bad, and it's especially a concern for autistics as they are more likely to be victims of sexual assault. Autistics are constantly taught as children that they need to ignore their bodily comfort and allow adults to touch them in various school and social situations in exchange for treats or to avoid punishment, what is that going to teach them? Likewise, if there is pressure to let people hug, kiss, or hold a child or else "make someone sad, and we don't want to make them sad do we," what is that going to teach? Also even outside of the grooming issues, touch can be physically painful or massively unpleasant for autistics - I have sensation issues and if tickled I will literally blackout and start thrashing, and I get super uncomfortable having most people touch me. It's awful, but so many relatives assumed that as I was a child they could do whatever they wanted and I was supposed to just ignore my own discomfort for their amusement. Again, this is not ok for non-autistic children either, but especially for autistics it's incredibly cruel, so making sure that kids don't get pressured into touching other people is key.

Food was also a recurring theme - as mentioned in a previous episode I really struggle with eating when out-sensoried, and the article we looked at Preference to Eat Alone: Autistic Adults' Desire for Freedom of Choice for a Peaceful Space found in their research that socializing, limited food options, and non-sensory friendly spaces could all make it harder for autistics to eat. How does that line up with holiday get-togethers?

Amanda shared "I'm unlikely to be very hungry if I'm eating at an unfamiliar time, off unfamiliar plates, potentially in uncomfortable clothing. I mostly managed this as a teenager by just not really eating during actual meal times and eating leftovers. It was very upsetting to me that this upset my parents because I felt like I was making an effort by staying downstairs to socialize with people and waiting to eat until later, and they felt like I was just making more

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mess just because I felt like it.” Yes! I personally mostly ate stuffing and gravy with peas as that was all I could manage on top of everything else. Food can be such a source of stress, giving autistics extra space here can be incredibly helpful, and don’t make comments drawing attention. Also, autistics - if you need to eat ahead of time, only eat bread rolls, or whatever to make things work, food isn’t morally good or bad and fed is best, especially for only a few afternoons or evenings a year. And definitely when someone decides to put almonds on the green beans. Why? Like, as a cook I actually get it, but from a texture-sensitive perspective my goodness why.

There were a lot of other references to unfamiliarity in Amanda’s quote which is very classic for many autistics, we often like to know the plan and it can be upsetting when it changes - when large parts of the world are actively hostile to your comfort, changes can be terrifying. There are huge shifts in routines around holidays, different spaces, eating at different times, and sometimes last-minute changes to plans, all of which can be super challenging.

Amanda also shared “Throwing me off my routine by making us not eat breakfast until after we’ve opened gifts is not helping with preventing meltdowns” - there are few things in this world harder for me mentally than having to be social first thing in the morning. I normally need my time to get settled, wake up properly, have my tea, and then I can people. Add in worries about eating before other people arrive, fears of not knowing the plan, and other discomfort and it can make things incredibly stressful!

This next comment however was so wonderful, Gina says, “As an adult with a child who is also possibly on the spectrum I limit all of this. Holidays are only celebrated in familiar environments and mostly only at my house where I can control schedules staying the same. I tell people that my son may “go off to his own room” but that he’s fine and please don’t bother him and I damn sure don’t get embarrassed by my children when they ask the way my parents did. I don’t

force my children to hug anyone unless they want to. I cook and if I know my son won’t eat something due to texture/smell/etc. I don’t force him to. I give him sensory toys to distract him during times of high stress and I try to have multiple “small” gatherings instead of one large gathering.” Oh my goodness I think I would have done anything for just a bit of that understanding as a child. Now, maybe that’s more than some autistics need, and others might love more people in some spaces, but...just being willing to tweak things to avoid meltdowns/crashes/mental health tanks is so incredibly wonderful.

Related to all this - holiday clothing is often different that what you’re normally used to wearing if you’re expected to dress up, and can frequently cause so many issues. I’m extra bitter about this one as I was constantly forced into wool tights and sweaters for the holidays and was a teenager before we found out I had a wool allergy. It was just ignored as me being finicky. Please, children are not dolls, don’t force any kid into something that upsets them that much when the main reason is you think it looks cute. Stephanie from Boston says “Let me help pick out my outfit, and try it all on together before I have to go to the thing.. I remember a few times having to wear knit tights that kept getting stuck on the velcro of my jacket and that’s all I remember about that year. Believe me when I explain that my hat is too small and that it hurts my head to wear it.” Physical sensations are different for us and may cause actual pain, through off our spatial awareness, and are a huge trigger for meltdowns - dressing up can mean many different things, it’s okay to want to look nice, but finding stuff that works for everyone is key. Tip for autistics - what fabric is comfy for you? I like cotton, linen, and rayon but not nylon, it feels sticky. Find a top in a material and texture you like but in a formal cut - several of my work blouses are cotton t-shirt material that have a tailored cut at the sides and a square neckline, or think non-wool sweaters in a thin material, a non-t plain cotton shirt but in a color matched to the celebration - you can be formal if your party requires it, but still comfortable rather than pushing yourself

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with something scratchy.

While not all holidays involve gifts, for ones that do this can be an extra challenge on multiple fronts. Amanda says “Just because my face isn’t doing what you expected it to do doesn’t mean I don’t like the gift you got me.” Also, “Giving me a longed for item related to my special interest first thing and then being upset that I don’t seem as engaged with the other gifts is counterproductive for both of us. I might really like those gifts too, but my focus has been captured by a particular thing” Both of these elements came up repeatedly in responses - as we’ve talked about before, autistic facial expressions are often different than non-autistic expressions, and especially if we are excited! Many of us who normally mask will forget to if we get interested in something, so an unusually flat affect may mean I am thoroughly engrossed in examining an item that I love! The more engaged we are the harder it can be to fake our reactions to things, so non-autistics, please don’t take it personally if our expressions or reactions aren’t what you expect.

I’ve seen people say that autistics who are uncomfortable around gift exchanges, it’s an example of our supposed lack of empathy, which, you know my thoughts there by this point, also this is a clear case of the double-empathy problem as autistics historically have given me great gifts but so many non-autistics have utterly failed. I often struggle with figuring out what the protocol is for gifts, and it makes things very stressful as I have a lot of trauma around social activities and being told I’m bad at them, so it’s incredibly nerve-wracking.

Things that can be helpful can be setting explicit guidelines for gifts and expectations - is there a price range, do folks have requests, is everyone present getting a gift for everyone else, only kids under a certain age, only direct relations, who? Taking the guess work out can be a huge relief.

Another important point, “Given all the talk about bad kids not getting any presents, it would have been

really helpful to have the fact that I was not a bad child more heartily reinforced” - likewise Rebecca says “The idea that only good kids get presents is too anxiety-inducing for an autistic kid (or honestly, any kid), since autistic kids already often have the experience of “failing” to live up to arbitrary expectations they don’t understand.”

While most of the responses I’m sharing were from adult autistics, a friend relayed her child’s request on this topic too, “Please stop insisting we must participate in your holiday parties if it makes me uncomfortable. Santa is absolutely not okay and you trying to make me sit with, talk to, or take photos with a stranger that has the authority to judge me as naughty is not okay.” Yeah, when you think of it that way Santa is terrifying.

As we’ve talked about before, autistics face so much trauma and pressure to conform, plus people calling us bad, broken, and evil for processing and reacting differently than non-autistics, this can be heartbreaking for a kid. Especially when combined with issues around non-autistics often not understanding our wishes, it’s easy to assume when you didn’t get what you hoped for it’s because you were a bad kid and didn’t deserve it. This can super mess you up. I literally picked up a whole philosophy major trying to understand if I was evil - oh, the humanities! (sorry, I really wanted to work that joke in there cause that got a little dark).

Lilith shared “Too many people unwrapping presents makes for stimulation overload because of the crinkling sound. Much prefer gift boxes or bags with minimal paper in them. That sound shreds my ears so bad.”

The sensory overload can be such an issue - I don’t have problems with paper (again, these are all individual experiences, any individual autistic may love some of these things), but Christmas lights are a huge thing in my area and my neighborhood has a competition for best decorations that people take

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very seriously. To be clear, I love my neighbors and they are great, but OMG flashing lights are just the worst for me. I cannot handle them, they make me uncomfortable and give me headaches - I actually have to cover my eyes with tv and movies sometimes when they do strobe or other flashing lights as effects because it triggers full migraines for me. Holiday lights aren't quite that bad, but the bright LEDS especially if they flash just is horrible. Also Christmas music everywhere drives me up a wall because a lot of it incorporates chimes/bells that are very high pitched, which is also a headache trigger for me.

I've been called a grinch in multiple settings because of this and I'm mostly ok with that because I know my limits are important for my mental health, but it's frustrating when people assume that folks who just want to opt out of a holiday are being mean when for a lot of folks, not just autism also survivors of childhood abuse especially it seems very common. So if I express frustration with blaring christmas music, or lights, or holiday sweaters that make me itch just to look at that I'm told we all need to wear, I shouldn't have to explain that for years I had red welts from the holiday clothing I "needed" to wear and it seriously makes me twitch to feel pushed to wear something like that, in order for someone to not insult me. Yes, let people enjoy things, but also let people not enjoy things without having to disclose their trauma or diagnosis.

We're all different, my roommate just got a sweater with snowmen murdering each other because she loves true crime, it's perfect for her and I am so happy for her, but that doesn't mean I should be pushed into wearing one too, or called a spoil-sport for not wanting to wear any sweater - also, especially because none of these holidays are universal and there are many folks who don't celebrate Christmas who shouldn't have to share their religion or lack thereof to avoid being shamed. I saw a great post on social media last week talking about how you can't claim to be pro neurodiversity or autism and then complain about

people being weird or cringe - most of us aren't bullied because of the label autism, we're bullied for liking something different, for talking differently, for being clumsy - the easy solution is to just not mock or belittle folks for harmless differences, regardless of diagnosis, ethnicity, religion, or anything else. Some people like different things, and it's ok to let people be different from you, and it's ok for us as adults to pick and choose what parts of holidays or traditions work for us, and what parts don't, either for us, or for our kids.

Now, with all that being said, for every experience shared here there will be autistics who are the exact opposite and love them - past guest, my sibling Katie loves getting people gifts, as does Heather, who says "I love how happy giving people presents that's stuff I think they will love makes them because I love gift giving just as much as I like getting presents" Heather also says "Actually for an autistic person I thrive during the holidays which I know is unusual and it's my favorite time of the year and I love everything about it but I'm also very social." So definitely use all of these as something to consider, but check in with autistics in your life directly - maybe it would be a huge relief if you agreed on a specific gift budget, maybe that would feel too mercenary, maybe the bright lights and music are amazing for a hypo-sensitive autistic and they would be super sad if things weren't there! Going back to that idea of neurodiversity, even just within autism there is so much diversity and variation in our preferences, needs, and desires, but giving us space to find our boundaries and support if what works for us might be different that what you expect, can make all the difference.

I'm recording this New Year's Eve and it will go live tomorrow, so from the Actually Autistic Educator and my seriously wonderful sponsor InterACTT, happy new year! Best wishes for 2022 - may it be better than the last, and filled with joy and comfort for you all. See you next month.