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Autistic Joy and Allistic Failure

Rosie O'Malley-Knudson

INTRODUCTION

In the wake of the waves of depression that have been disabling Americans over the past few decades, the medical community has failed to investigate a real and possible solution, at even the most basic of levels. Autism is a profoundly misunderstood disability due to the systemic misrepresentations of it in media, diagnostic biases, and crucially, lack of research (Haney, 2015, DSM-5). Furthermore, autistic joy is virtually unheard of in medical and academic settings. Autistic joy is the sense of elation or euphoria unique to autistic people, typically experienced when engaging in special interests and realized with stimming. Stims, formally self-stimulatory behaviors, are sense-based means of emotional regulation. Autistic people tend to stim in patterned ways not associated with allistic (non-autistic) people, ie. hand flapping, vocalizing, rocking etc. however, it is important to note that everyone stims (Kapp et al., 2019, Abstract). Some common allistic presentations of stimming are laughing when happy, rubbing temples when stressed, and tapping a foot when anxious. Autistic joy does not have an allistic equivalent, but despite this, is woefully under researched and respected in the medical community. The expansive research of autistic depression with the absence of the same studies of autistic joy is representative of the ableist attitudes of American academia and medicine. There is a need for a bridge between the work being published informally by autistic people and the work being peer reviewed by academics and medical professionals.

BREAK

Time to process and practice stimming. Find something you can already see that is pretty or otherwise visually stimulating and enjoy it. Continue reading.

METHODOLOGY

This research began on social media, where far-reaching communities of autistic people converge to share experiences. The term autistic joy was popularized by autistic advocate Chloe Hayden in the summer of 2023. While autistic joy has not always been named as such, the specific sense of euphoria experienced by autistic people is well-documented throughout history. It is repeatedly mentioned in Leo Kanner's 1943 published paper that first defined autism as a

neurotype, as one of the pivotal characterizations of the autistic children he studied. Kanner himself describes that Donald Triplett, the first person to be diagnosed as autistic, “jumped up and down in ecstasy as he watched [toys] spin” (Kanner, 1943, 218). Kanner’s notation of this enjoyment is a rarity in medical spaces, but central to many in-community discussions of autism.

The assets of autistic joy and its sheer power are celebrated in autistic spaces, so when searching “autistic joy” on blogs and social medias, countless anecdotes and ways to engage in it are recalled. Moving away from the online space, a book titled *Stories of Autistic Joy* was recently published in 2024 compiled by Laura Kate Dale. This book provides even more evidence of autistic joy’s impact.

When looking for modern scientific based approaches, “autistic joy” does not yield results in many respected databases or academic journals. Searching instead for “serotonin and autism,” “happy stimming,” and “SSRIs and autism” does bear some related articles, however. The common results were chemical-based studies on serotonin and other chemicals in autistic brains, and proposed “solutions” to found imbalances and differences from the standard levels in neurotypical brains. Moving away from technical writing, there are also many accessible articles on stimming aimed at parents of young children. These aid in understanding the layperson’s understanding of autism as dictated by medical and academic opinion.

BREAK

*Time to process and practice stimming. Think of a song you love, hum it if you can.
Continue reading.*

HISTORIOGRAPHY

The term “autistic joy” is relatively new, but studies on autistic emotional reactions or lack thereof are well documented. There are esteemed research groups dedicated to studying autistics’ brain chemistry in an attempt to learn why autistic people socialize differently. However, these organizations are overwhelmingly run by allistic people and use a deficit-based model, an example of this being Autism By The Numbers (“Autism Speaks, National Autism”, 2023). The goal is oftentimes to uncover “solutions” to “normalize” autistic brain chemistry, focusing on autistic depression and dysregulation. The opposites of autistic joy are autistic melt/shutdowns, which are highly researched and pathologized. Oftentimes, they are “treated” to

match neurotypical standards with selective serotonin reuptake inhibitors (SSRIs). Of all diagnosed autistic people, 32% (~24 million) are prescribed SSRIs (Nadeau et al., 2013, “SSRI treatment of ASDs”). Additionally, there is evidence to suggest that SSRIs have no positive benefits to autistic children, and there are, in fact, emerging studies showing an adverse effect on taking SSRIs as a child (Williams et al., 2010, author’s conclusion). Despite this, SSRIs continue to be the most prescribed medication to autistic people, typically due to a (questionably researched) medical condition called hyperserotonemia. This is an alleged endophenotype of autism, where one’s blood has elevated levels of serotonin. It is medically misunderstood, with few quantitative studies. Theoretically, SSRIs help the body to regulate and access its serotonin, but in practice this is unproven for autistic children.

An article published by TIME Magazine in 2013 examines a Stanford study that suggests chemical differences in autistic individuals. The article summarizes the study, with the main takeaway being oxytocin (oddly, the hormone that surges during an orgasm-this will come up again later) is likely to work in combination with SSRIs to “lead to more improvements in behavior” in autistic people. It goes further to say that starting this concoction of medications “early enough can even change brain activity to resemble more normal patterns that find social interactions rewarding and satisfying” (Szalavitz, 2013, para. 11). Put more simply, this is a vote of support for giving autistic children SSRIs and oxytocin so they can socialize like allistic people, instead of addressing why the children find most social interactions unbearable. The specific language of forcing brain activity to “resemble more normal patterns” in children is reminiscent of attempts to “cure” autistic children instead of adapting for them. Also relevant, but unmentioned, are the studies that show many autistic people do get significant reward (arguably more than allistics) from social interactions, as long as their interactions are within the same neurotype (Crompton et al., 2020, abstract). This is to say that autistic people communicating with one another have higher rates of perceived rapport when compared to inter-neurotype interactions and purely allistic interactions. In this specific case, obviously the 2013 article could not reference the one from 2020, but the attitudes that led to the findings were not new at the time the first article was published.

Moving away from scientific studies does not combat the ableism in the medical community. For new parents learning about their autistic child’s recent diagnosis, hundreds of articles are at the ready. One such article published by Verywell Health includes a helpful graphic

for the viewers, with four recommendations to “manage” a child’s stims. In order of appearance, it suggests Applied Behavior Analysis (techniques from this “therapy” inspired the punishments prescribed in conversion therapy), occupational therapy, medication to treat underlying anxiety (like the aforementioned SSRIs), and finally, adapting the environment to the child’s needs (Gilmartin, 2023, graphic). This article is also, as of when this paper is being written, the first Google result when one looks up “happy stimming.” While this article was clearly designed to be more accessible than the scientific studies on autism, it comes to similar conclusions about autistic emotional expression being negative and worth controlling, with the positives of autism -like autistic joy- being nonexistent. This recommended control or management consistently manifests as medicating children with drugs that have unknown or negative long term effects, as opposed to working with the built-in override that autistic people have through their special interests. This is harmful for countless reasons that will be explored later in this paper, but first it is important to examine what less formal sources say about autistic joy.

BREAK

Time to process and practice stimming. Take a sip of a drink or chew some gum and notice how it feels in your mouth. Continue reading.

HISTORIOGRAPHY CONTINUED

Within the autistic community, there is little to no scientific study into the chemical reactions associated with autistic joy, but countless anecdotes of its unique effect. The reasons that autistic people are not the ones researching themselves and why the medical community is so out of touch with the people it attempts to help are too expansive to be explored in this paper. Generally, it is agreed upon that barriers to autistic people in the workforce and the systemic ableism in the medical field are at play. This leaves autistic individuals with fewer “credible” platforms on which to publish their experiences with joy. Social media and the internet act as a bridge between autistic people across the world, and quickly became a hub of in-community knowledge.

Stimming in the autistic community is generally seen as a positive because it aids in regulation, and happy stimming (stimming to express overwhelming joy) is particularly valuable. An autistic individual eloquently describes autism as his “brain’s love letter to [his] heart”

explaining that with his autism, he experiences “hardship...but also unparalleled joy” (Josephs via Dale, 2024, p. 98-99). Paige Layle is an autistic advocate and influencer from Canada who makes educational content about autism. In one of her Youtube videos on stimming, she explains that, while not remotely sexual, stimming “can have the same kind of appeal, or the same kind of release and happiness that having an orgasm does” (Layle, 2021, 8:23). This comparison, along with comparisons to masturbation and sex, is one of the most common ones when explaining autistic joy to a neurotypical audience. In fact, when Leo Kanner wrote his findings about the eleven autistic children he observed, he described their “ecstatic fervor” as an indication of “masturbatory orgasmic gratification” (Kanner, 1943, 246). It is again important to note that this comparison is truly a comparison of release, not sensuality. As stated before, there is no allistic equivalent, but this is theoretically as close as it gets. Despite this, there have been no published studies into the chemical reactions that occur when someone happy stims. Even with the consistent comparisons to orgasm, there is no data as to whether or not oxytocin levels, the chemical released during an orgasm, fluctuate during stimming.

In July of 2023, Chloe Hayden made a TikTok of herself happy stimming and watching a pod of whales, with overlaid text about autistic joy, specifically including “autistic joy is the most unadulterated joy in the world.” This video has since gotten over five million views on TikTok and Instagram. While responses from autistic social media users were overwhelmingly positive, many allistic viewers took her video as an opportunity to mock autism and unmasking (the process of no longer hiding or suppressing autistic traits). The abuse was so severe that Hayden made a response video, explaining that the hateful reactions happened “because the idea of autistic joy -of a disabled person living and existing in ways that make sense to them- is still deemed completely, entirely wrong.” She went on to say that she had received “at least fifty death threats because of this video of [her] flapping [her] hands” and reminded her audience that “autistic people are nine times more likely to die by suicide” and that because of that, her “life expectancy is 35” (Hayden, 2023, Instagram). While this was over six months ago, it is still the pinned post on her Instagram as of May 2024.

BREAK

Time to process and practice stimming. Touch a texture you enjoy, whether that's something you're wearing, something else in the room with you, or even something outside. Continue reading.

ANALYSIS

Autistic joy has been pervasively ignored in medicine, science, and academia. Years of research have gone into trying to mold autistic people to meet the neurotypical standard of mental health and social ability, despite autistic people being explicit about a tool they have that is being underused. People are scrambling to manage the outbreak of mental illness in this country, particularly among youth (World Health Organization, 2022), but have failed to look at a potential solution that has already worked in the autistic community.

Autistic melt and shutdowns are the opposite of autistic joy. Melt and shutdowns are an overwhelm of negative input while autistic joy is the overwhelm of positive. Instead of seeing the two extremes as in tandem with one another and working within autistic people's default emotional processes to manage dysregulation, many medical experts instead ignore autistic joy and instead consider melt and shutdowns a lapse from the neurotypical standard.

Autistic joy is a powerful aspect of autism that is just as integral to the neurotype as melt and shutdowns. It is widely agreed upon in-community that joy is an effective tool in delaying or avoiding melt and shutdowns entirely. If the efforts at standardizing autistic people were instead redirected to understanding the chemicals behind autistic joy and the brain when a person happy stims, there is a real possibility that the benefit would extend far beyond the autistic community. There are skyrocketing cases of "treatment resistant" mental illnesses, that despite the arguably blame-oriented label, really just require treatments that, as of yet, are undiscovered. Autistic people have been asking the medical community to view and treat them as equal, independent people with excruciatingly slow success. It is time to frame the lack of research into autistic joy as the data gap that it is. A data gap that hurts everyone, allistic and autistic people alike.

BREAK

Time to process and practice stimming. Think of five words that are fun to say, try articulating them in different accents or intonations. Continue reading.

CONCLUSION

The overlap between autism and depression cannot and should not be denied. It's estimated that autistic people "are 4-times more likely to experience depression in their lifetime" (Hudson et al., 2019, Abstract). There are neurological differences that have gone unstudied and a plethora of societal factors that cause autistic people to become depressed. However, this should lend credence to autistics' endorsement of autistic joy, not detract from it. Put bluntly, autistic people are born with a built-in "fix it" system. It should be given the respect it deserves.

My earliest memory of autistic joy is when I couldn't have been older than seven, alone in my bedroom with my Christmas lights having just been hung. They were red, yellow, green, and blue, and I controlled their twinkling with a big remote dial. I was so purely happy I felt like my excitement was going to burst out of my body, and in a way it did. I stim danced, which is exactly what it sounds like, letting the anticipation and energy work its way through me, then ran to the living room to ask my mom if being excited for Christmas was normal. Even as a kid, alone in my bedroom, I was worried about normalcy. Instead of understanding my joy as an asset -I could get kid-left-in-a-candy-store levels of excitement from looking at the same lights I had stared at a million times before- I saw it as an oddity. The stigma around neurodivergent expressions of joy is pervasive and is not going unnoticed by people, whether they realize it or not. Even before I knew any of the words I now have to describe my special interests, I knew that my experience with joy was intense and focused and not something I had seen in anyone else before.

The false narratives about neurodivergent emoting are creating tangible harm in the practical world. The messages of how to "manage" stimming, "normalize" autistic socialization, and "cure" autism are not going unheard. They tell autistic adults that their lived experiences with joy don't matter, and that they are intrinsically less than their neurotypical peers. They tell autistic kids that they are broken in some way. They tell the parents of autistic children that their child is flawed and encourage extreme action (and abuse in the case of ABA) to make them fit in. They tell doctors that autistic kids require early intervention and should overmedicate developing brains. They tell the general public that they possess a superior neurotype, which lends itself to hierarchical views of humans and, in extreme cases, eugenics ideals. Those messages also tell the public that because they are superior, they are beyond help when

something does go wrong. After all, why would someone look for answers in the brain of someone “lesser than?”

Autistic people have been erased and sidelined, our stories mistold or just missing. To tell any story of autism without autistic joy is to further the martyrdom narrative of autistic people and the actual martyrdom of people experiencing untreated mental illnesses. It is urgently important that steps be taken to shrink the data gap between autistic deficits and autistic strengths.

LAST BREAK

One more time allotted to process and practice stimming. Do something that helps your brain or body relax. Anything.

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