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The Autism Epidemic

Abstract

Reported cases of autism spectrum disorders (ASD) have skyrocketed over the last decade, leaving those afflicted and their families curious as to why. Health care professionals have deemed the rise in ASD an epidemic calling much attention to the autistic community. But is it appropriate to equate autism with some of history's worst and most deadly pathogens? Autism is a disorder, not a disease that can be spread rapidly through person-person interaction. This rise in prevalence can be explained due to broadened diagnostic criteria, increased awareness, and better diagnostic techniques. In addition, those apart of the autistic community are now being stigmatized by those ill-informed about ASD. Therefore, the term epidemic is very misleading and should not be used to explain the rising number of autism spectrum disorder cases.

Many parents raise their children and discover it unusual for their child to be distant and unresponsive to facial expressions or exciting moments; to not be able to express proper emotions to certain situations. As most parents do, they take their child to the doctor for an examination to receive an explanation behind their child's abnormal behavior. The last thing they were expecting to hear was their child being diagnosed with an autism spectrum disorder. According to the Center of Disease Control and Prevention (CDC) in Atlanta, on average, approximately 1 in 88 live births were diagnosed with autism as of 2008 (Baio para 4). As shown in figure one, the rate of autism has increased at an astonishing rate since the 1970s. Because of its high incidence rate, parents, researchers, and those affected by the disorders are starting to become more concerned.

Autism has affected many people across the globe for many years. The number has been increasing drastically, and researchers have been trying to find an explanation behind why this is so. The significant rise has been termed an "epidemic" by scholars everywhere. This raises the question why should the rise in autism be considered an epidemic? Leading developmental psychologist, Uta Frith, mentions that "most experts believe that the increasing prevalence

figures that have been found over time do not reflect a real increase in cases” (59). If there has been no increase in cases, there has to be a logical reason explaining the increasing number of autism spectrum disorder cases. There has been one theory that has been supported explaining the surge of autism spectrum disorder diagnoses. Since there is no scientific evidence behind the enigma, “the number of diagnosed cases of autism arises from nothing other than [intentional] broadening of the diagnostic criteria, coupled with deliberately greater public awareness, and conscientiously improved case finding” (Gernsbacher et al. 1). So can this really be termed an epidemic?

Author and anthropologist Roy Richard Grinker, in his book *Unstrange Mind: Remapping the World of Autism*, offers a new insight on autism that differs from the idea of autism as an epidemic. He insists that the rise in autism diagnoses should be viewed as a positive occurrence because it means scientists, doctors, and epidemiologists are diagnosing and counting autism better than ever before (Grinker 3); the current numbers being compared to historical figures will look skewed because before the 1980s, autism went undiagnosed or misdiagnosed more often than not (Grinker 3). Therefore, the word epidemic is being misused. As health conditions and diseases, such as autism, start to become more prevalent in the United States, researchers and epidemiologists have loosely described the rapid increases as an epidemic, which has been supported by faulty data (Fombonne 2). Grinker states, “the definition of epidemic has broadened (147). Now we use the word with little reference to the speed at which new cases are occurring, which puts us one step away from the original usage” (147). By definition, epidemic means “an outbreak of disease that spreads quickly, [occurs suddenly], and affects many individuals at the same time” (Merriam-Webster; Grinker 147). Since a cause has not been linked to autism and autism does not spread from person to person, autism cannot legitimately be

considered a disease, therefore, disabling it from being labeled an epidemic. The term epidemic itself “implies danger and indicates fear, calling up associations with plagues that can sweep through the streets, something contagious in the air you breathe, or in the food you eat, threatening the ones you love” (Grinker 5). None of these atrocities associated with an epidemic fairly describe autism.

While an explanation for autism does need to be found, scaring people in the process by labeling it the start of an epidemic is not necessary. Citizens should not be misled into thinking autism can be passed through the air and can be caught by everyone. The term epidemic is very misleading and should not be used to explain the rising number of autism spectrum disorder cases.

Individuals with autism have been identified for tens of thousands of years. Their strange behavior was never exactly understood, but was more a spectacle to be observed. Leo Kanner and Hans Asperger were the first to publish works on childhood autism in 1943 and 1944, respectively, after observing children with special, unexplained characteristics. Coincidentally, they both used the term “autistic” to describe the behavior of the children. The word “autistic” or “autism” stems from the Greek word *autos* meaning “self” (Frith 5). A common feature observed among autistic children was the inability to identify with others and the outside world, an extreme that allowed the individual to exclude all surroundings except the person’s own self (Frith 5). Kanner and Asperger were both able to identify children with unique features such as these, and their findings were widely accepted and used later to recognize children with Kanner’s autism as well as Asperger’s Disorder (AD).

Across the globe today, “many societies do not have a word for autism, and in others the symptoms of autism are not thought to be abnormal as much as divine or spiritual” (Grinker 3).

In most countries, though, there are diagnostic criteria widely used to define autism and similar psychological disorders. The most common are the *International Statistical Classification of Diseases and Related Health Problems* (ICD) and the *Diagnostic and Statistical Manual* (DSM). They both agree that the “impairments of social interaction, communication, and imagination and the rigid, repetitive patterns of activities are crucial diagnostic features” (Wing 27) in recognizing autism spectrum disorders (ASD). Even though each diagnostic book shares these common criteria, it is still disputed among psychologists and psychiatrists about the proper boundaries to put in place in order to distinguish between different disorders since ASD symptoms can range from mild to severe (see figure two). The terms high-functioning autism (HFA) and the diagnosis of AD are relatively new in the United States, just being added to the DSM in 1994 (Bagatell 3).

Terror. Fear. Parental concern. These are the words associated with the worst epidemics in history such as the bubonic plague, small pox, and polio. Today the word epidemic has been paired with conditions like obesity and autism to describe their increasing prevalence numbers. Regarding autism, reported diagnostic cases have increased 78% from 2002 to 2008 (Baio para 40). Even though these number are valid, a question has to be raised as to whether is it appropriate to categorize autism as an epidemic; should autism be equated with a fatal killer such as cholera?

Discrepancies can be made between the types of epidemiological studies used to describe the rise in ASD cases. In the case of autism, most of the studies conducted have been prevalence studies as opposed to incidence studies (Grinker 148). Prevalence studies produce rates that refer to the proportion of a population affected by a certain disease at a single point in time (Shields 1)- for example 1 in 88 children are diagnosed with ASD (Baio para 3), while incidence studies,

however, are the number of *new* cases of a certain disease over a given time period (Shields 1). For instance, if an epidemiologist would survey a specific area for a disease, then return a few years later, he or she would be studying those who contracted the disease that did not have it previously; the number of new cases.

Because prevalence studies are primarily being used to describe the rise in ASD, the numbers seem to be increasing more drastically than realistically. ASD cannot be compared to other real epidemics in history because comparing the statistics would be inaccurate and misleading- aside from the fact autism does not pose a threat to the lives of the undiagnosed. Therefore, by supporting the rise in ASD diagnoses with prevalence studies, the term epidemic is being socially constructed to explain the autism enigma and as a result gain attention of the public.

Many researchers, reporters, and doctors have coined the high prevalence of autism as an epidemic, but have not found scientific evidence as to why. Many hypotheses have developed regarding why autism is on the rise- vaccinations, environmental factors, and genetic inheritance. These explanations have lost their footing as their research shows there is no causation between these risk factors and autism spectrum disorders: prenatal exposure to ethyl-mercury from thimerosal-containing vaccines was not related to increased risk for autism spectrum disorders (Price et al. 9); though correlation has been reported between environmental factors and autism, symptoms do not prove it to be a cause of autism (Frith 73); and genetic factors cannot explain the large short term increase in autism diagnoses (Eyal et al. 17). One hypothesis now being explored by psychologists has promising results: the rise in autism spectrum disorders is caused by the broadening of diagnostic criteria, increased public awareness, and improved case findings

(Gernsbacher et al. 1), not because it is being contracted by a virus or environmental toxin.

Hence, the autism epidemic cannot be tangible if the causes are as stated.

After Kanner's and Asperger's findings, a new wave of interest developed for autism; psychiatrists were finally starting to lose their monopoly over the field of the mentally ill and mentally retarded. Parents, clinicians, and therapists pushed to have autism dismissed as a form of mental retardation, but a rare condition that occupied the space between the mentally ill and the mentally retarded (Eyal et al. 56). As their influence grew, their goal was undermined by the deinstitutionalization of the mentally retarded. Now there was a plethora of mentally ill children that all fit under the autistic criteria; the distinction parents fought hard for was now ineffective. Eyal and his colleagues explain that "within the new institutional matrix that replaced custodial institutions- a matrix composed of early intervention, socially innovative therapies, special education, and community treatment- autism became differentiated from mental retardation and generalized into a spectrum, laying the groundwork for diagnostic substitution in the 1990s" (Eyal et al. 57). All the newly released patients had to be accommodated. Because autism was now non-distinguishable from the newly released mentally retarded population, the prevalence of autism spectrum disorders skyrocketed as awareness spread from the early 1970s to now. So it is not that autism was spread from person to person, the diagnostic criteria simply grouped together numerous diagnoses creating the autism spectrum.

Though it is understood autism cannot be passed through the air, others try to support the existence of the autism epidemic with scientific studies claiming autism can be passed behaviorally. Sociologist Ka-Yuet Lui and his research partners explored this notion: if a "normal" child is in close proximity with an autistic child, the parents of the "normal" child will start seeing similar behavioral patterns between the two children and seek assistance for their

perfectly “normal” child. There is a possibility this is a plausible hypothesis because “diagnosis relies on the recognition of a range of behavioral symptoms that vary greatly from case to case, that are increasingly heterogeneous, [and] that are more difficult to isolate because age of diagnosis has declined” (Lui et al. 1). Even if there is not a viral or environmental influence that explains the spread of autism, it can be supported through social contexts.

The only problem with this argument is it is too “ad hoc” (Eyal et al. 52). This study can be applied loosely to all forms of illnesses; it already has been applied to other learning disorders (Ong-Dean 2) as well as bipolar disorder (Groopman para 1). Parents are able to express concern concerning their child’s development, but should only be supported through sufficient diagnostic evidence. Information about autism, autistic symptoms, and services for the autistic can be spread orally from parent to parent. As a result, some “parents may advance a medical model of disability as a legitimate way of explaining and classifying a child’s difficulties, [even if there is nothing wrong with their child], to recognize the rights and needs of disabled people, sometimes against the authority of professional medicine itself” (Ong-Dean 2). In this case, the wrongly diagnosed child cannot contribute to the non-existent autism epidemic because autism was not spread, but only thought to exist.

Since autism has been classified as an epidemic, many people are now aware that autism spectrum disorders exist; that children and adults diagnosed with autism are in need of an explanation of their symptoms; and parents are forced to live with extreme financial debts because of the continuous therapy they put their child through without the help of insurance companies. Is this really why autism is classified as an epidemic? Parents have advocated continuously for politicians and therapists to be on their side in support of the idea autism is a burden for the afflicted, and sometimes they have ignored their cries for help. However,

influential politicians and celebrities that so happen to be parents of autistic children have successfully raised awareness about autism. Since autism became more visible, there is more reason to manipulate autism as a more severe disorder in dire need of a cure. Increased awareness lead to the start of classifying autism as an epidemic in 1999 to the response of misleading figures released by the Department of Developmental Services (DDS) in California (Grinker 143).

Even before autism was classified as an epidemic, a stronger connection between the autistic community and their advocates grew tremendously. They had a reason to push for legislation to be passed, research to be done, and extra services to be given because diagnoses have reached epidemic level proportions. When an issue is constantly evaluated from a methodological standpoint, “the construction and management of scientific evidence is a key aspect of the implementation of disability policy” (Baker and Stokes 9). It all started with the Developmental Disability Act that provided resources for the mentally ill and associated disorders. Initially, autism was not recognized as being congruent with mental retardation because advocates fought endlessly to differentiate autism from other neurological disorders. Since no benefits were being allocated for autistic children, autism advocates quickly identified autism as being “akin to mental retardation in being ‘neurological’” and had scientific evidence from prestigious child psychiatrist, Donald Cohen (Eyal et al. 198). Therefore, Congress had no choice but to include autism as apart of the legislation.

Autism has been manipulated because ASD was more visible than ever. Awareness spread about autism to the point where it was recognized on a political level. As a result, many stakeholders emerged that claimed to be adversely affected by the rise in ASD, making it harder to ignore. Since autism advocates already successfully captured the attention of many, why call

autism an epidemic? As Grinker states in an interview, “calling autism an epidemic is a fictional tool for fundraising; a scheme to call added attention to a disorder” (Grinker para 7). No one is going to argue against the rise in ASD cases, because taking a stance against the disabled is a set-up for social suicide. After publishing *Unstrange Minds: Remapping the World of Autism* where he challenges the idea of autism as an epidemic, Grinker was “accused of betraying the autistic community and deemed a traitor” (Grinker para 7). Since, autism has gained enough support to be acknowledged on scientific, social, and political levels, advocates are willing to manipulate the severity of autism by associating extreme labels with the disorder. Even though classifying autism as an epidemic gives the disorder the attention it needs, it also creates negative attention for those who are considered apart of the epidemic.

Families with disabled persons have two very difficult jobs: caring for the afflicted individual and coping with the stigmas placed on them by society. As many know, children with autism have a normal appearance- passersby would not be able to identify them as autistic as they would a child with Down’s Syndrome. This contributes to why ASD are the most stigmatized disorders amongst adolescents.

Throughout history, instances of shame associated with autism was heard about but never discussed or acknowledged. It was common practice for affluent families to institutionalize their mentally retarded children in secret to protect their family legacy. Sociologist David Gray indicates in his study “autism has uniquely stigmatizing aspects because of the extremely disruptive nature of autistic symptoms, the normal physical appearance of autistic children, and the lack of public knowledge and understanding regarding the nature of autism” (Gray 102). Since autistic people have no distinct outward appearance, when they misbehave onlookers

categorize their parents as bad parents unable to control their child. Sixteen of the twenty-nine selected parents in Gray's study felt stigmatized because of their child's illness (Gray 108).

Since its inception, the autistic community has come very far in terms of becoming integrated and accepted in society. Many stigmas have been eliminated allowing for this to happen. Now with autism being labeled an epidemic, it allows for the reemergence of stigmas to once again divide the normal from the impaired. For any disability, "stigma is a branding, a way that society marks us for transgressing the bounds of what is considered normal" (Grinker 69). It permits for a hierarchy to be established, distinguishing the better from the worse. Labeling a whole group of people as part of an epidemic is insulting. It stigmatizes them and makes them feel as though they are a detriment to society (Chew para 4). Professor Nancy Bagatell of Quinnipiac University has already gained insight about how the autistic community feels about being autistic. After talking with a young man at an Autistic Adults Coming Together (AACT) meeting, Bagatell described one of the members, Harold, as being relieved he was diagnosed with autism because it allowed him to "better understand himself, gain insight into his strengths and challenges, as well as locate others like himself" (3). If there are others like Harold who feel relieved to be autistic, a cure does not need to be found. More investing should be geared toward accommodating and integrating the autistic community, not shaming them by labeling them apart of an epidemic.

If we allow the autistic community to integrate themselves in society, it will create the potential opportunity for "autistic people to have a powerful voice in how society conceives of what autism is and what it means to live with autism" (Bagatell 34). People ill-informed about what autism will finally be brought into the light, and hopefully their thoughts will be changed for the better. Therefore, not labeling autism an epidemic can create a system where the autistic

community will continue to be incorporated into society, ultimately dismantling stigmas from being formed against them.

Epidemic should not be a word that is thrown around lightly. Words chosen to describe a particular disorder do matter, and should be taken into careful consideration. Autism is not an epidemic, and should be referred to as something else. Grinker gives an insightful view of how autism has evolved and is perceived to the outside world. He states, “the term epidemic has changed with culture and what society interprets as a disease” (Grinker 3). It is being manipulated to increase concern of the general public about autism spectrum disorders. Without such a serious word that grabs the attention of many, this concern would not matter to those not affected. Ever since the term epidemic has been paired with autism, it gives political, economical, scientific, and even social influences the opportunity to get involved. They believe “an epidemic” is in their jurisdiction. Categorizing ASD was a “politically determined process—so is, ultimately, the autism epidemic” (Eyal et al. 65).

When people hear the word autism, they do not immediately think of it as a contagion. More so, people would associate autism with an individual who lacks the ability to communicate with others, but are safe to come into contact with. Increased awareness of autism allows the afflicted as well as those not diagnosed to be recognized. So recognize them by calling them citizens, friends, and neighbors. Let the research continue, but not in the light that autistic people need a cure, because they do not. As described by Bagatell, “autism is seen as a fundamental part of who [the diagnosed] are, not just something that they have; that is, if their autism were eliminated they would not be the same person” (38). So the problem lies with society and not in the heart of the autistic community. Let us call it what it is: the rise in ASD prevalence is a revolution; a way of defying normalcy that will eventually have to be accepted and integrated by

those who consider themselves normal.

Appendix

Figure 1: This graph shows the major increase in autism diagnoses from 1975 to 2009. There is still minimal explanation as to why the increase has been so drastic. Source: Autism Speaks.

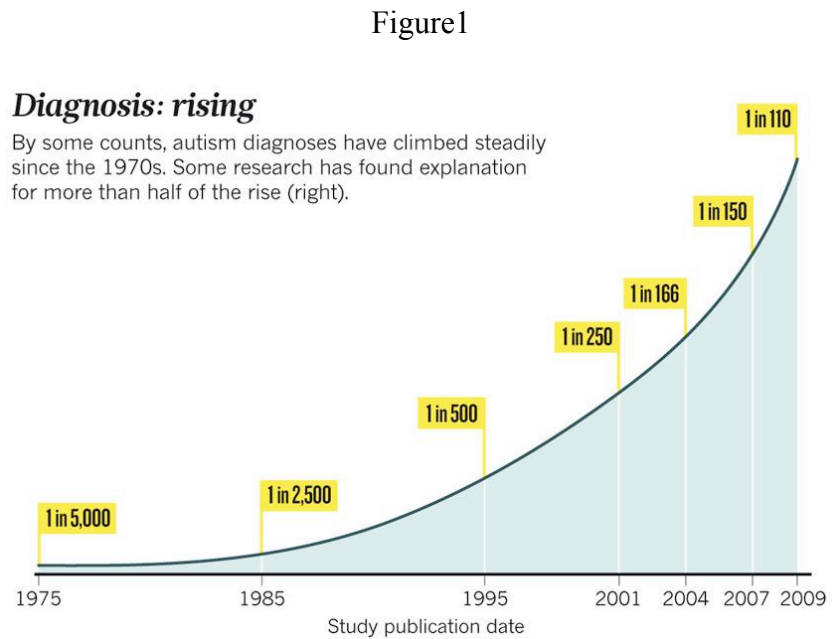
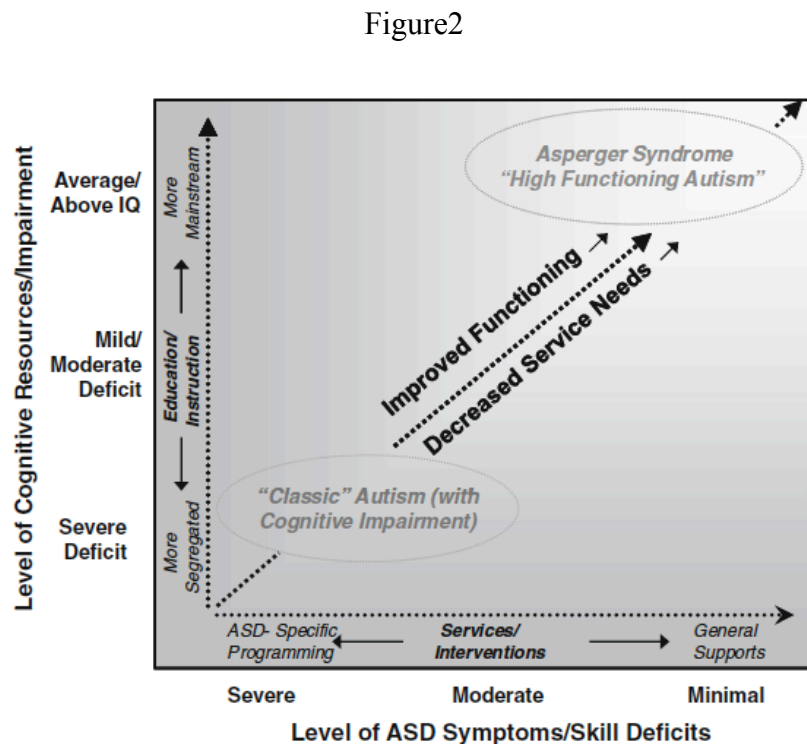


Figure 2: This graph shows the varying symptomatic levels of autism spectrum disorders, from severe to very minimal



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