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The Path to Diagnosis: A Case Study of Two Children with Autism

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The Path to Diagnosis: A Case Study of Two Children with Autism

Abstract

In recent years there have been a growing number of individuals that are being diagnosed with autism. It is interesting that autism did not seem to be as prevalent in society just a few years ago. In order to best determine why autism is more common, the cause of autism must be examined. Currently, the exact cause of autism is unknown; however, the most likely theory at the time is genetics. Understanding why autism occurs will help further research on why the number of individuals with autism might be growing. After reviewing the case studies of two families with children who have been diagnosed with autism, there are many similarities found that may account for the rise in diagnosis of autism. Further research is required in order to draw an accurate conclusion regarding the increase in autism diagnoses.

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The Path to Diagnosis:
A Case Study of Two Children with Autism

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Abstract

In recent years there have been a growing number of individuals that are being diagnosed with autism. It is interesting that autism did not seem to be as prevalent in society just a few years ago. In order to best determine why autism is more common, the cause of autism must be examined. Currently, the exact cause of autism is unknown; however, the most likely theory at the time is genetics. Understanding why autism occurs will help further research on why the number of individuals with autism might be growing. After reviewing the case studies of two families with children who have been diagnosed with autism, there are many similarities found that may account for the rise in diagnosis of autism. Further research is required in order to draw an accurate conclusion regarding the increase in autism diagnoses.

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Introduction

Autism is a disability that is becoming more prevalent in our society. There seems to be an increasing number of children who are diagnosed with autism than there have been in years past. Educators are more likely to have a student with autism at some point during their career. Often, educators are the first people who recognize that a student might have a disability. Knowing the reasons for the increasing number of children being diagnosed with autism could potentially help a teacher as well as other professionals and parents make a correct decision about a student with autism.

It is possible that what seems to be a rise in diagnosing autism is actually a misdiagnosis. Alternatively, it is possible that diagnoses are on the rise due to autism awareness. There are many different organizations that have developed in our society that have provided awareness of autism. With the growing number of people who have access to information on autism, perhaps there is a correlation to the number of parents and teachers who are able to identify the symptoms of autism. In order to understand why the number of individuals who are diagnosed with autism is increasing, it is imperative to examine the path that lead to those children being diagnosed with autism.

Access to resources might also play a role in why a child is diagnosed with autism. If a parent has access to certain doctors, school personnel, or information, they might be more likely to have their child diagnosed with autism than a parent who has access to different resources or to no resources at all. The resources that are available to a parent might influence the diagnosing of autism and could also explain the reason for an increase in individuals who are diagnosed with autism.

Each child who is diagnosed with autism has a story. By learning the story of the individual who is diagnosed one can learn a lot about what led to the child being diagnosed with autism and this could potentially lead to why there are a growing number of individuals who are diagnosed with autism in our society.

The Causes of Autism:

A Review of the Literature

Autism is a disability that is characterized by a deficiency in social skills; people who have autism showcase a wide range of abilities. A commonly used term for the various ways autism presents is Autism Spectrum Disorder (ASD). The use of spectrum in the name implies the wide range of abilities that is seen among individuals with this disability. The spectrum includes childhood autism, atypical autism, and Asperger syndrome as the main categories on the spectrum (Mouridsen, Rich & Isager, 2009). Autism has had an existence for many years and there are possible cases of autism that date back to A.D. 250. While these accounts were not formally documented, there are stories of “feral children” that lead researchers to believe there may have been cases of autism, found most commonly amongst boys, who grew up socially isolated (Koegel, 2008). Since the first formal documentation of autism, there have been an increasing number of individuals who are diagnosed with autism. Many people are questioning why there is what seems to be a sudden increase in ASD. In order to understand why diagnosis of ASD is on the rise, it is important to examine what causes autism. However, at this time there is no formal answer to the question of what causes autism. There are many theories of what might cause someone to exhibit the characteristics of autism. Researchers have hypothesized many different possible causes and they range from vaccinations to genetics. The cause, however, is

still unknown and there is plenty of research to support many different theories of what causes autism and what might be causing the increase of diagnosis.

One of the first theories that people think of when discussing the possible causes of autism is vaccines. The long term side effects of vaccinations are sometimes unknown. Parents who are looking to identify what caused their child to have autism might turn to this theory for an explanation. However, this explanation holds no truth. According to Kemp, and Hart (2010), there is not a link between the vaccination given to children for measles, mumps and rubella and Pervasive Developmental Disorders (PDD) such as ASD. They dispelled the myth that was created in 1998 by a British gastroenterologist, Dr. Andrew Wakefield. Dr. Wakefield published a paper in *The Lancet*, and in his publication he theorized that there was a link between the measles, mumps, and rubella (MMR) vaccines and the development of autism. This created panic amongst parents in both Europe and the United States. People became skeptical of the MMR vaccine and other vaccinations. Not only did Dr. Wakefield's publication support this theory, so did the coincidental increase of children being diagnosed with autism and the increase of children who were receiving the MMR vaccination. Since then there have been a number of different studies conducted that disprove this theory(Kemp & Hart, 2010).

To demine whether the theory of the link between MMR and autism was indeed true, Kemp and Hart (2010) conducted a review of studies conducted by other scientists. Their findings indicated that there were 1,010 children who received the MMR vaccination prior to their diagnoses with autism, whereas, there were 3,671 children who had the MMR vaccination after their diagnosis. This study also found that there were similar chances for children to develop and be diagnosed with autism if they were given the vaccination or not. The research

concluded that there was no link between the MMR vaccination and autism. *The Lancet* made a correction to their claim in February of 2010 (Kemp & Hart, 2010).

The theory of the MMR vaccination being an unlikely cause of the rise in autism leads researchers to look for other possible answers. Could it be an environmental cause or is it part of a person's genetic makeup? Perhaps it is a combination of both. These ideas are some of the other possibilities that have been explored by researchers.

Steyaert and De La Marche (2008), suggest that "ASD is a disorder with mainly genetic causes and recent insights show that a variety of genetic mechanisms may be involved, i.e. single gene disorders, copy number variations, and polygenic mechanisms" (p. 1091). As technology advances, it is becoming easier to identify the different genes that cause certain characteristics in humans. It is possible that genetics plays a role in what we know as autism.

In order to test whether ASD is inherited, twin studies have been conducted. In their research, Steyaert and De La Marche (2008) found evidence supporting a high inheritability rate for ASD. The findings show that there is a 70% concordance rate for autism in monozygotic twins. Among siblings there is an approximately 2-8% chance of recurrence in a family with one sibling who has autism (Steyaert & De La marche, 2008). There is also note of evidence that suggests that if one family member has one symptom of ASD but is not markedly impaired there is a higher chance of autism being inherited (Steyaert & De La marche, 2008). This evidence suggests that genetics plays a role in autism and that relatives of an individual with autism are more likely to inherit autism.

The genome is complex and as with many different traits that people inherit, it is not always one gene that accounts for a said trait. It might be multiple genes working together to create the trait. That being said, it is most likely the case that autism is caused by genetics.

According to Steyaert and De La marche (2008), “These finding suggest a complex heritability of autism, and it is possible that different genes and biological pathways contribute to different parts of the ASD phenotype,” (p. 1093). There is research to suggest that many different genes are combined to make what is known as autism. After testing the inheritability of ASD, they concluded that there is more than one gene that is responsible for ASD. The fact that autism might be cause by genetics could lead to the reason why there are more diagnosed cases of autism. If genetics plays a role in autism it is a possibility that there are more potential carries for autism because of the inheriting of the genes that cause autism.

Studies have been conducted to explore the sibling to gender ratio of children who have autism. The study’s intent was to give researchers insight on to the number of siblings who were male or female with autism and thus help to explain the ratio proportion of male children diagnosed with autism to the number of female children with autism. The male to female ratio of children diagnosed with autism has been reported to be anywhere from 1.3:1 to 16:1, but a mean of 4:1 has been reported (Mouridsen, et al., 2009). In any case there is approximately four times the number of males diagnosed with autism than females. The question that scientist puzzle over is why there are more males than females with the diagnosis of autism. In their study, Mouridsen, et al. (2010), concluded that out of 513 siblings there were 300 males and 213 females that were diagnosed with autism and that there was no association with the IQ in autistic probands. Mouridsen,et al. (2010), discuss that there are two possible theories to account for the sex differences in ASD prevalence rates. The first is, The X-linked imprinting theory of autism has been advanced by Skuse (Mouridsen, S. E., Rich, B., & Isager, T.) who proposed an explanation for male vulnerability to ASD that is based on the fact that males have a single X chromosome,” (Mouridsen, et al., 2009, p. 291). Males are more likely to develop X liked

disorders and therefore this theory would explain why there are more males diagnosed with autism than females. The second theory that is discussed by Mouridsen, et al.(2010), is when the affected fetus were in utero they were exposed to high levels of testosterone. “The study has demonstrated that fetal testosterone levels measure in women, who had amniocentesis for other reasons, was associated with autistic traits in their offspring,” (Mouridsen, et al., 2009). Mothers who have had amniocentesis had babies where there was a correlation between the testosterone levels and autistic traits. There is a possibility that an excess exposure to testosterone would account for the reason why there are higher numbers of male children diagnosed with autism than female children who are diagnosed. There is no question that a higher number of males than females are diagnosed with autism.

In a similar study, it was concluded that there are many children with ASD that also have a learning disability or genetic disorders associated with learning disabilities. Learning disabilities are most commonly inherited because of Fragile X syndrome (FXS) (Caglayan, 2010). Caglayan (2010), states that:

approximately 90% of male children with FXS show one or more features of autism (e.g. atypical social interactions, lack of eye contact, social anxiety and avoidance, preservative speech, stereotypic behavior [e.g. hand flapping], hypersensitivity to sensory stimuli, impulsive aggression, or self-injurious hand biting). (p. 131)

It is understood that there is a high percentage of children who have a learning disability and exhibit at least one of the characteristics of autism. The findings lead researchers to believe that there might be a link between the genetic defects on the X chromosome and autism.

There are many X linked disorders where the person who had the disorder also exhibits one or more traits of autism. These include Rett syndrome, Prader-Willi and

Angelmansyndromes, Inv dup(15) or idic(15) syndrome, Down syndrome, Joubert syndrome, Neurofibromatosis type 1, Macrocephaly and overgrowth syndromes, Timothy syndrome, tuberous sclerosis complex with autism, Turner syndrome, Williams syndrome, Smith-Magenissyndrome, Klinefelter syndrome, XYY syndrome, 22q13.3 deletion syndrome, Smith-Lemli-Opitz syndrome, Cohen syndrome, Phenylketonuria, Sanfilippo syndrome, Adenylosuccinatelyase deficiency, Duchenne muscular dystrophy, Mitochondrial cytopathies, and non-syndromic causes of autism (Caglayan, 2010). With all of the different X chromosome related disorders, it is a possibility that the increasing number of diagnosed cases of autism might be due to a misdiagnosis of the disorder. Perhaps why autism has been on a rise is due to the symptoms of other disorders being misdiagnosed as autism and the fact that people a long time ago may not have shown as many symptoms of autism because they did not live as long as they do now with the other X chromosome disorders. With technology people diagnosed with these X chromosome disorders could be living longer and having more time to show and develop autism like symptoms that are misdiagnosed as ASD which may account for the rise in the number of individuals with autism.

Another theory addressed by Charlotte Schubert (2008), is that the male biological clock might be linked to autism. It is commonly known that women who wait until later in life to bear children are more likely to give birth to children who have Down Syndrome. This leads to the question of whether or not there might be similar occurrence with men as they age. Spontaneous mutations can happen in both egg and sperm and it is estimated that by the time a man is 50 years of age the stem cells that sperm are derived from have divided 840 times. With this many divisions, it is much more likely that a mutation will occur (Schubert, 2008). If Autism is caused by a mutation in the genetic material passed from parent to offspring, than a man who has been

living longer with more chance for cell division to create mutations, there would be a higher chance of having a child with autism.

In today's society, it is not uncommon for men and women to wait longer to have children. Men and women are more likely to date more, "move up" in their careers and gain higher education before settling down with a companion. Once people find someone to spend time with and have children with they are more likely to spend time building their relationship and wait to have children. With these choices men and women are having children later in life rather than in days gone by when men and women were more likely to settle down and start a family early on. With men becoming fathers later, if there were a link between the male biological clock and autism it could very well explain why there have been a seemingly increasing number of individuals diagnosed with autism.

With all of the unexplored territory of the genome, many different disabilities and characteristics of humans can be hypothesized to have a relation with some aspects of genetics and a possible gene that would be the cause. However, there is still so much to be explored with genetics and their link to autism that other theories will be postulated. There are other theories that attempt to explain the increase in the number of children being diagnosed with autism.

The influx of children diagnosed with autism might have to do with external environmental factors. In a study conducted in Texas, it was shown that there are lower rates of Hispanic children diagnosed with autism than there are of non-Hispanic white children (Palmer, Walker, mandell, Bayles, & Miller, 2010). If genetics were the cause of autism, there should be a more equal number of Hispanic and non-Hispanic white children who are diagnosed with autism. However, the rise in number of children diagnosed with autism is more prevalent in non-Hispanic white children.

The cause for more non-Hispanic white children being diagnosed with autism than Hispanic children in Texas was researched. The findings concluded by Plamer, et al. (2010) stated that, “increasing percentages of Hispanics in school districts remained a significant inverse predictor of autism prevalence even after adjustment for socioeconomic and health care provider factors,” (p. 270). If there were to be an increase of children in a school, and autism was linked strictly to genetic factors, the increase in school population should show an increase in the number of children who exhibited autism. However, the findings indicate that as the number of Hispanic children in the school district grew, the number of children with autism did not grow. This leads researchers to believe that there are other factors that are involved in the diagnosis of autism and what accounts for the influx in children diagnosed with autism.

Research has shown that socioeconomic factors might play a role in the number of children that are diagnosed with autism. From their results, Palmer, et al., (2010), concluded that, “higher socioeconomic status and density of local diagnostic physicians explain differences in autism rates for non-Hispanic Whites but not for Hispanics,” (p. 271). Their research is showing that there is an increase of non-Hispanic Whites being diagnosed with autism because of the resources that they are able to obtain. It is possible that the reason for lower numbers of Hispanic students being diagnosed with autism has to do with socioeconomic factors such as health care delivery that have yet to be examined (Palmer, et al., 2010). When examining the number of individuals that are diagnosed with autism, there are a number of factors that contribute to whether a child has been diagnosed or not. It is possible that there is an under reporting of data about students who had autism (Palmer, et al., 2010). Further research on the subject of socioeconomic factors involved with links to the increased numbers of children diagnosed with autism will help to determine some of the discrepancies.

A different, yet similar perspective on the increasing rates of autism is addressed in *Is Autism the Disability That Breaks Part C? A Commentary on "Infants and Toddlers With Autism Spectrum Disorder: early Identification and Early Intervention" by Boyd, Odom, Humphreys, and Sam*, discussed in an article by Schwartz and Sandal (2010). In their writing, Schwartz and Sandall address what different types of services should be provided to children who are diagnosed with autism prior beginning school and if all families with children diagnosed with autism have access to the same resources. However, they also address the theory that socioeconomic factors might play a role in the reason for an increase in autism diagnosis. There is an underlying message that families who have more education gain more access to resources for their children with autism than families that receive only Part C Early Intervention Resources. There are increasing numbers of children who are in need of the Part C funding for resources due to a diagnosis in autism, however there remain more people who in addition utilize resources of their own (Schwartz & Sandall, 2010). Having more education and money could lead to more resources and therefore increased number of diagnoses.

There is a belief or theory that autism is cured by diet. The thought is that if a child with autism is feed a gluten-free/casein-free diet than they will be "cured." This is a misconception. If a change in diet cured autism than the cause would have to do with a dietary imbalances or something related to food. However, this diet only helps some of the symptoms that are associated with autism; therefore autism is not caused by diet. However, a gluten-free/casein-free diet is useful in combating symptoms of autism because a commonly comorbid diseases with autism is a gastrointestinal (GI) diseases. The GI issues are caused by allergies to certain foods. There are two types of allergies. The one that is most commonly thought of when discussing allergies is where the cells inflame immediately and cause the symptoms that are most

often associated with an allergic reaction; this is known as an immediate reaction. The other type of allergic reaction, delayed-type reactions, the symptoms of the reaction do not manifest in the body until several hours later (Jyonouchi, 2010). The gluten-free/casein-free diet helps with the allergic reactions to food caused by the comorbid GI issues that are common with autism. Autism has no direct link to food and diet and would not impact a rise in the numbers of children being diagnosed with autism.

Another possibility for the rise in the number of children being diagnosed with autism could be the way in which autism is diagnosed. Perhaps there is a flaw in the testing and methods that are used to diagnose autism. If the methods for diagnosing autism are subjective then it is possible that the increase number of people being diagnosed with autism is due to this subjectivity in the diagnosing of autism, or, perhaps the cause for the rise in autism has to do with the methods for diagnosis. According to Pasco (2010), if the rise in diagnoses of autism is due to the means of diagnosing it, in order for autism to be increasing, there must be an indication that a change in how a case of autism was diagnosed is in correlation to the rise in numbers of individuals with autism being diagnosed. This meaning, if there was a change in practice in how a physician or psychologist diagnosed autism, shortly after this change in practice occurred, there would be a rise in the number of individuals that are being diagnosed. However, the research has shown that this is not the case (Pasco, 2010). There is no sound evidence between when practices have changed in the past and the increased number of individuals being diagnosed. Pasco (2010) states, “the level of increase remains unexplained and that there is a need for more and better studies,” (p. 11). Without further studies about how the increasing number of cases of diagnosed autism correlates with the changes in how societies

diagnose autism, there will be an unknown, unconformable possibility of what might be the reason for the increasing numbers of individuals that have been diagnosed.

Currently there are two primary ways for determining the diagnosis of autism. The two different ways of diagnosing autism are explored in the writings of Saemundsen, Pállmagnússon, Smári, and Sigurdardóttir (2003), and the diagnostic tools are the Autism Diagnostic Interview-Revised (ADI-R) and Childhood Autism Rating Scale (CARS). The ADI-R is used in determining the diagnosis of autism based on the World Health Organization (WHO) and the American Psychiatric Associations' (APA) definition of autism. It is a standardized instrument that is designed to provide an algorithm. The Childhood Autism Rating Scale was developed for use by TEACCH program in North Carolina and is based on a pre-ICD-10/DSM-IV conception of autism (Saemundsen, et al., 2003). In reference of the two diagnostic tools Saemundsen, et al. (2003) stated, "Both of these instruments are widely used, but data on their agreement are sparse" (p. 319). This would indicate that there has not been much research done in order to determine if the two tools used in diagnosing autism due so in a similar fashion and if they do so based on similar criteria. Without further data collection in this area it is hard to determine if this would be a possible cause for an increase of children being diagnosed with autism. If it were, however, a means for an increase number of children being diagnosed with autism it would indicate that one of the two diagnostic tools either, the ADI-R or CARS, was proven to be an unreliable source. Whichever test was unreliable would be skewing the numbers of people who truly had autism. This could then be a possible reason for the increase in diagnosed cases of autism.

In order to gain more clarity on the discrepancies that might exist between the ADI-R and CARS, Semundsen et al. (2003), did some research in order to find the agreement between the

two diagnostic tools. Their findings indicate that there were indeed discrepancies between the two diagnostic tools. One of the areas studied was the male to female ratio that was diagnosed by each diagnostic test. It was found that the ADI-R had a male to female ratio of 3.5:1. This is very consistent with what is found amongst actual diagnosed individuals with autism.

However, the group of children studied that had been diagnosed with autism via the CARS indicated that there was much higher ratio of boys to girls that were diagnosed. It was a 17:1 boy to girl ratio finding (Saemundsen et al., 2003). These findings would indicate that if a girl was to be diagnosed only using the CARS that she would be less likely to be diagnosed with autism. However, if there were many boys that were being tested for autism by means of the CARS only than there is a possibility that there are more boys being diagnosed with autism than truly have autism, and this might be a reason for the influx of children being diagnosed with autism. There were discrepancies between the two diagnostic tools in the areas of nonverbal verses verbal subjects, and IQ. However, the overall findings indicated that there were more cases of autism diagnosed when only using CARS as opposed to ADI-R or both ADI-R together and when CARS was the only diagnostic tool used the symptoms of autism were more severe and the IQ was lower (Saemundsen et al., 2003). In conclusion of this study it is stated that there are higher rates of autism that are found when using only CARS to diagnose children. Perhaps the increase of individuals diagnosed with autism is due to the fact that more professionals are only using CARS to determine a diagnosis of autism. However, there would need to be more information in order to make this theory a conclusive reason for the increasing numbers of individuals with autism.

According to Ann Le Couteur, Gyles Haden, Donna Hammal and Helen McConachie (2008), in order to make an accurate diagnosis of autism it must be a multidisciplinary approach

that has a procedure that includes assessments of cognitive and language abilities, observations of functioning across many different settings, as well as the detailed developmental history and description of current behaviors. This might include standardized instruments as well as the clinical judgment of a minimum of two professionals who are experts in the field of autism (Le Couteur et al., 2008). The word “judgment” means to make a decision or opinion based on research and sensible decisions. All people think differently and there might be different interpretations of the same data when making a judgment. In the cause of diagnosing autism it would make sense that more than one individual would be consulted when deciding whether a child has autism or not. Although, the more individuals that are able to observe and interact with the child and make a judgment the more accurate a diagnosis of autism can be. It is possible that more children are being diagnosed with autism because there are more individuals in the professional field that are biased towards a diagnosis to autism. If professionals are “searching” for autism they might be more likely to find it and then make a judgment in favor of autism. This in result could lead to higher incidences of autism.

Discrepancies to diagnostics could also be made in other aspects of the diagnostic process as well. In their discussion of what ADI-R is in comparison to Autism Diagnostic Observation Schedule (ADOS), LeCouteur et al. (2008) stated that,

Currently the ADI-R provides a summary diagnostic algorithm that distinguishes between Autism and not Autism. The ADOS is a play and activity based assessment that provides, through the specification of ‘social presses’, standard context for observation of aspects of social behavior, communication, play and restricted and repetitive behaviors in individuals (across the ability range) suspected of having a possible ASD. (p. 363)

In this explanation of the diagnostic tool, ADI-R, there is room to interpret that there is more to diagnostics than the tools that are currently used in order to determine if autism is present. The word “suspected” means that there is no certain ruling that a child has autism, only that there are individuals out there that have made a judgment that a child might have autism, this person might be a parent or family member, teacher, doctor or other professional that might work with the child. This leaves room for personal biases and interpretation of what might be considered autism. The suspension of autism combined with other theories might be a reason for the increasing number of children who are diagnosed with autism.

If someone suspects that a child has autism, what is it that is causing this individual to believe that the child has autism? The increase in diagnosis of autism might go back to the access to resources. With all of the current research about autism and our societies wealth of technological access there are more individuals who are becoming educated about autism. If people are able to access sources that give information about autism, they are more likely to make an assumption that a child has autism. Their decision might be based off of correct research or incorrect research; however, if they suspect it they are more likely to have the child tested. More children being tested and recognized would lead to the increase in the number of children who are diagnosed. Prior to the access to information quickly and easily there would be less access to this information and people might be less likely to suspect a child had autism. In order to prove the theory to be true there would need to be research done that would show a correlation between people who are educated about autism and the increasing number of children who are diagnosed with autism.

The question of what is causing an increase in the diagnosis of autism is yet to be answered. More research needs to be done in order to confirm the answer to this puzzling question. Perhaps it is some combination of parts of more than one of these theories.

Autism is a disability that is characterized by a deficiency in social skills; people who have autism showcase a wide range of abilities. This can lead to a lot of subjectivity when searching for a diagnosis and might be a reason for this increase. Perhaps there is not an increase in individuals with autism. If the very early documentation of “feral children” by early sources are true, than it is possible that there were many cases that were not documented and it is because of society and technology that more cases of autism are documented and known about. Of course it is still important to understand what causes autism in order to best understand why there is a rise in the number of diagnosed cases of autism. Until there is a concrete understanding of what causes autism there will remain a question of what causes the rise in the numbers. There are many theories of what might cause someone to exhibit the characteristics of autism. The research has hypothesized many different possible causes that include the MMR vaccination, genetics, X-linked diseases, the male biological clock, access to resources, diet, the way in which autism is diagnosed and subjectivity of who has autism based on access to resources and the diagnostic procedures. While research has ruled out some of these theories such as diet and the MMR vaccination there are still many areas that are in need of exploration. Further research in the other possible causes is in need. The most likely cause that is being researched is genetics, however, it will be some time before scientists are able to pin point the exact genetic combinations that would be responsible for autism. The cause, however, is still unknown. With continued study on autism the mystery of what causes autism will be determined and then

researchers will be able to focus on determining what is causing the rising numbers of individuals who are diagnosed with autism. Until then the mystery remains.

Method

In order to determine what factors may influence how a child is diagnosed with autism and whether that might be a reason there are a seemingly increasing number of individuals that are being diagnosed with autism, data must be analyzed. In this particular study, two sets of parents will be interviewed as a means of finding out how their child was diagnosed with autism. Each participant will be asked to discuss the paths that led their child to being diagnosed with autism. This data will be analyzed to determine if there are any factors such as resources available and education of parents that might have contributed to the child being diagnosed. The findings will help to conclude the reason to why there is an increase in the number of individuals being diagnosed with autism.

Results

Karen* is the mother of a daughter who has autism (personal interview, March 2, 2011). Her daughter, Melissa*, was diagnosed with autism around her third birthday. When Melissa was about 15 months old, Karen began to notice that Melissa had behaviors that did not seem to be typical for a child at that stage of development. It was stated that Melissa would “act strange.” These behaviors were noticed soon after Melissa was given a series of vaccines. Karen had heard about the possibility of vaccinations being the cause of autism. This was in the back of her mind as she watched her daughter develop. Karen began to notice that there was no eye contact from her daughter; she would not look at people when called. Her daughter would also participate in repetitive behaviors. This included doing a puzzle and then dumping it and starting

* Names have been changed to protect confidentiality.

the puzzle over again. These untypical behaviors had Karen concerned and she began to research what might be causing the behaviors in her child.

The notion that her daughter might have autism was primarily based on internet research. Though her readings on the internet, Karen learned a lot about autism and the symptoms and this had her thinking about her own daughter and the behaviors her daughter presented. Karen also read about autism in books. Prior to her extensive internet research Karen's knowledge of autism was based on a movie she had seen. With her new knowledge and concern for her daughter Karen sought out answers from her pediatrician.

The pediatrician did not believe that Melissa had autism. The pediatrician told Karen that all children develop differently and that Melissa at most had a speech delay. Karen took the pediatrician's advice and found a speech therapist for Melissa as well as finding an occupational therapist (OT). Both of the therapists were specialized in working with children who had autism. It was the OT that suggested that Karen bring Melissa to see a developmental pediatrician, who ultimately was the one to diagnose Melissa with autism. Melissa began therapy sessions and there were great strides seen in her development. The speech therapist recommended a program at a local university that focused on one to one behavioral therapy. Melissa was also enrolled in an early childhood education program when she was three. Melissa was learning quickly at the program and the program discharged Melissa. According to Karen, the early childhood program was not as helpful in Melissa's development as the speech therapy and the occupational therapy were.

In the process to help Melissa develop as typically as possible, Karen also tried nutritional supplements. Using the supplements supports the theory that perhaps diet would be

able to help some of Melissa's symptoms. However, this was not really found to help the symptoms.

Since Melissa has been diagnosed with autism, Karen has learned that there have been studies done that have proven there is no connection between vaccinations and autism. Karen feels that autism might in fact be caused by genetics. Since the diagnosis of her daughter she has noticed similar symptoms in her brother. Karen feels that her brother's characteristics fit many of the characteristics that are common among people with Asperger's Syndrome. These characteristics included few friends growing up, very bright, shy, and limited speech. Karen said that she had not thought of her brother being on the autism spectrum until her daughter was diagnosed with autism.

Melissa is currently home schooled and has shown much improvement in her development. She is nine and is a middle child with an older brother and sister as well as a younger brother and sister. Karen was offered to have Melissa attend school in a classroom with ten other children, but Karen felt that this placement was not appropriate because the students in her opinion only had speech delays. Karen has chosen to home school her children and feels this is best for her daughter's development.

Bill* is the father of a son who has autism (personal interview, March 5, 2011). His son, Pete*, was diagnosed with autism between the age of three and three and a half years old. When Pete was about one, Bill started to notice that there was something different in the development of Pete versus his twin sister. It appeared as though Pete was "in his own world." Pete appeared distant to his father and mother. Pete not only appeared to be in his own world, but he was not developing the same as his sister, he would rock and when they would call his name they would not get a response. Bill was concerned that Pete had a hearing issue because he did not respond;

*Names have been changed to protect confidentiality.

this however was not the case. Bill noticed that the symptoms that his son had were shortly after he received vaccines. Bill thinks that perhaps the mercury from the shots was what caused his son to have autism. If the shot had more mercury than another shot it could explain why Pete had autism and Alicia did not. The other theory that Bill is a strong believer of is the idea that autism is perhaps linked to diet and toxins in the body that enter the body through the lining of the stomach and intestines, because Bill noticed that the symptoms started around the same time that Pete began eating table food. Bill feels that perhaps the reason that Pete has autism and Alicia does not is because of the fact that Pete has a more sensitive stomach so certain foods, such as foods with red dyes, have more of an effect on Pete. When Bill had noticed there was something different in Pete's development, he spent a lot of time at Barnes & Noble researching his son's symptoms and thought that autism might be a fit and developed his theories on why it might be autism. Bill said that books were the easiest way to do research because his computer at the time was slow and therefore it was more frustrating to do internet research, however, if he were to have had the computer he has now he would have done more internet research. Prior to his research, Bill said he did not really know anything about autism and his wife stated that she only had seen a few people with autism in movies.

Bill took this information to his pediatrician and asked if perhaps his son had autism. The pediatrician did not seem worried about the development of Pete. It was Bill and his wife who pushed for referrals for an autism specialist. They found an autism specialist who was affiliated with a local hospital that diagnosed Pete with autism. Pete was then referred to Pre-Kindergarten and Kindergarten program for students with autism. It was in this class that Pete began to grow and develop.

Bill was concerned about his son having the “tag” of special needs, but is not concerned anymore because he has seen the benefits that his son has received because of it. Pete is currently in a classroom where he receives one to one help, extra help and the people who work with him are positive and cooperative. Pete is currently doing well with school and stated that he enjoyed school, especially math class. He also stated that he did not have very many friends, but he said that was okay with him because sometimes friends get you in trouble. Pete said that his sister was his friend and that he enjoyed playing with her on the playground.

Discussion

There are many similarities between the stories of how both Melissa and Pete were diagnosed with autism. The similarities between the two cases and the discussion with parents have created some questions in my mind as well as some theories about what may be causing the rising number of individuals who are diagnosed with autism. The findings of the interviews have given me some different perspective on what might be causing the rise in autism.

One of the similarities between the two families that were interviewed is the fact that both parents became concerned that there might be something different about their child’s development after the children received their vaccinations. Both parents had heard the study and theory that the mercury in the vaccinations was the cause of autism. It is now known that the vaccinations do not cause autism in children, however, at the time of the children’s diagnosis this was a theory that parents had access to. Parents are concerned about the well-being of their children. It is possible that many parents heard the same theory of the vaccinations causing autism and were soon concerned about the fact that their children might have autism. Concerned parents might have done research about autism and what the symptoms are of autism. With their heightened awareness, parents may have noticed the symptoms of autism portrayed by their

children that they might not have otherwise noticed. With the newly discovered symptoms and concern for their children, they have gone to get the opinion of a doctor or other professional. With more parents aware of the symptoms because of the vaccination scare it is possible that more children were diagnosed with autism.

Another possible reason for the rise of children who are diagnosed with autism is the access to information. In the first interview, I learned that the primary way that Karen learned about autism was from the internet. Our society's ability to gain information quickly and easily has given many people access to information that they would not otherwise have had access too. Perhaps the reason that there are a growing number of individuals diagnosed with autism is correlated to the introduction of the internet. When I was younger, the internet was just beginning to come about. I do not recall knowing anyone with autism or hearing about autism. When I was a senior in high school, I started to learn about autism through one of my classes at school and at this time the internet was a resource that was highly used by many people. With access to the internet, parents who are concerned about their children are able to look up information on all sorts of topics. If a parent felt that there was something different about their child, it would be easy for that parent to go to their computer and have a wealth of knowledge at their fingertips. With this knowledge, it would be easy for them to learn about autism and if the parent felt that their child was presenting with symptoms that sounded like autism, they would likely go to seek out the opinion of a doctor or other professional. The internet may have given many people information about autism that they might not have otherwise known and thus leading to the rise in the number of individuals who are diagnosed with autism.

Similar to the idea that the internet has given further accesses to information on autism is the access to information in books. In the second interview I learned that Bill learned about

autism because of books that he picked up at Barnes & Noble. Several decades ago, stores and big shopping malls were not as prevalent as they are now. There has always been the library to have access to books, but now there are many large book retailers for people to go to and buy books about whatever topic strikes their interest. If someone goes to one of the retailers and the book is not available, the retailer will order the book for you. In today's society, a person has the ability to obtain almost anything they can imagine and this includes books that are written on autism. A parent is able to go to a book store and buy many different books on autism. When my parents were growing up, books stores like Barnes & Noble did not exist and autism did not seem to be as prevalent. In today's world, there are many more shopping centers, malls, and books stores, and there appears to be more individuals with autism. Is autism on the rise because of the ability people have to access resources about autism and to learn about it and then go seek out further opinions about whether or not their child has autism? It is possible that the way we as a society are able to gain information has led parents to gain information and be more aware of symptoms of autism ultimately leading to the rise in the number of individuals being diagnosed.

Similarly, it is possible that autism is not on the rise, it is just more publicized. Many people discuss past generations and how crime was lower, there were fewer children kidnapped, and how other similar events occurred less. In conjunction with that many people believe that it is not that the world has become a less safe place, but that it with all of our various ways of communication, there is more publication of these occurrences. Therefore, perhaps it is not that autism is on the rise, but that autism is more publicized on the news, in books, magazines the internet and other various sources making appear as if autism is on the rise.

Prior to conducting the interviews, I thought that I would interview the parents and that the parents would tell me that they brought their child for a checkup with the pediatrician and that

was how they learned about autism. However, that was not the case, neither parent learned about autism from their doctor's office. They did not read pamphlets in the waiting room or have the doctor tell them that their child had autism. In both scenarios, the parents were the ones who asked the doctors if their child had autism. In Karen's case, the doctors told her that her daughter only had a speech delay. In Bill's case, his pediatrician told him that his son was just delayed. Both Karen and Bill wanted a second opinion and sought out specialist in order to receive a second opinion. In both cases, it was the specialist who diagnosed the children with autism.

This finding leads me to believe that the rise in the number of people with autism could be caused by one of two things. The first reason is that the more information that parents have and the more they are educated on the symptoms of autism the more likely they are to recognize it and bring it up to their pediatricians. The pediatricians, however, may not know a lot about autism. A pediatrician is going to know and be educated in medicine concerning physical disease and traumatic injury, and have relatively less time in school devoted to developmental problems. They may have learned a little bit about autism, but chances are that would not have been their primary focus in medical school. Therefore, the pediatrician may not have known as much about autism and would not have felt comfortable diagnosing autism. If parents are aware that there might be something wrong with their child and they believe their child has autism, they will want to go to find someone who has more knowledge in autism to be sure that they are getting a more accurate assessment of their child. With the gained knowledge in autism, more parents will be going to seek out specialists.

The second theory I have about this is that the knowledge about autism may be leading to misdiagnosing of autism. Perhaps the rising number of individuals with autism has to do with the fact that people have access to information and over analyze it. It is possible that parents are

learning about autism by books, friends, television, or online, and are then finding the characteristics of autism in their children. If they had not learned about autism, they might not have even noticed a characteristic or thought that there was anything different with their child. The rise in autism might be caused by parents who are learning about autism and certain that their child has autism. They would then search for a professional who will give them the answer that they want to hear. This would mean that the number of people with autism is not really on the rise, but the number of people being diagnosed appears to be on the rise because of misdiagnosis.

Conclusion

Autism has been around for many years, however, in recent years it appears that autism is on the rise. Scientists and researchers have a lot more to discover about autism and what causes it as well as why it appears that autism is more commonly diagnosed than it was in past years. There was a time when people believed that autism was caused by the MRR vaccination, however, research has proven this to be untrue. Currently scientist and researchers have theorized that the cause of autism is due to genetics. The genetic make-up of an individual is complex and possibly scientists will someday be able to understand all of the workings of the human genome. Until it is understood what exactly causes autism, it will be hard to determine why it autism appears to be more common among people today.

The findings from the interviews suggest implications for teachers are going to be targeted mostly towards early childhood educators. Both of the parents that were interviewed stated that their child was diagnosed with autism around the age of three. This is the age when many young children are just starting to go to school in early childhood programs. These

programs will need educators that are familiar with autism and are knowledgeable in the best practices for working with children who have autism. If there truly is a rise in the number of individuals being diagnosed with autism it will mean that educators in general will need to be up to date and knowledgeable on the best teaching practices for working with children with autism. If the number of children is on a rise, it is more likely that a teacher will teach a student who has autism.

If I were to do further research, I would survey more parents who have nine year olds that have autism. It would be interesting to see if there would be the same similarities between the diagnosis processes, or if the results were different. It would be interesting if the scare about the MMR vaccination was the reason for the rise in the number of individuals being diagnosed. If the majority of parents were worried about autism after vaccinations then they might have sought out someone in order to find out if their child had autism.

It also would be interesting to take a look at when the internet started to become more prevalent in our society and see if there is a trend between the number of individuals diagnosed in a year and the popularity of the internet. This would help to further prove whether or not autism is on the rise because of the information that people have access to. Similar studies could be conducted to find out if the rise in autism has to do with a correlation between bookstores becoming more accessible and the number of individuals diagnosed with autism. A study could also be performed to shed light on whether or not the ability to communicate news and information in general has a correlation with the number of individuals being diagnosed with autism.

Further studies could also be done on what pediatricians know about autism and if they often refer people to other specialists who might know more about autism. This could help

determine if autism was actually on the rise or if it is being misdiagnosed. If pediatricians are in fact able to accurately diagnose autism, it is possible that parental determination to get their child “labeled” with autism could be a factor in the increase in diagnosis rate, due to these kind of parents seeking out additional specialists until they get the answer they think they need.

After my research on the topic, I have determined that further research would need to be done in order to have a better understanding of why autism is on the rise. Interviewing and surveying more parents would be a start. However, in order to know for sure what is causing autism to be more commonly diagnosed it is essential to understand what causes autism. Is it an external factor or is it part of our complex genetic make-up? If it is an external factor that causes autism, what is it and why would it be more prevalent now than it has been in the past? If it is genetic, there are many reasons that genes for autism have become more present among people. Or perhaps, autism is not actually occurring more often, but is just being diagnosed more often than in the past or misdiagnosed. Once again, this would be much easier to determine if we knew the exact cause of autism.

References

- Caglayan, A. O. (2010). Genetic causes of syndromic and non-syndromic autism. *Developmental Medicine and Child Neurology*, 130-138.
- Jyonouchi, H. (2010). Autism spectrum disorders and allergy: observation from a pediatric allergy/immunology clinic. *Expert Reviews*, 397-411.
- Kemp, M. L., & Hart, B. (2010). MMR vaccine and autism: Is there a link? *JAAPA*, 48 & 50.
- Koegel. (2008). Evidence Suggesting the Existence of Asperger Syndrome in the Mid-1800s. *Journal of Positive Behavior Interventions*, 270-272.
- Le Courteur, A., Haden, G., Hammal, D., & McConachie, H. (2008). Diagnosing autism spectrum disorders in pre-school children using two standardised assessment instruments: the ADI-R and the ADOS. *Journal of Autism and Developmental Disorders*, 362-372.
- Mouridsen, S. E., Rich, B., & Isager, T. (2009). Sibling sex ratio of individuals diagnosed with autism spectrum disorder as children. *Developmental medicine and Child Neurology*, 289-292.
- Palmer, R. F., Walker, T., mandell, D., Bayles, B., & Miller, C. S. (2010). Explaining Low Rates of Autism Among Hispanic Schoolchildren in Texas. *American Journal of Public Health*, 270-272.
- Pasco, G. (2010). Identification and diagnosis of autism spectrum disorders: an update. *Pediatric Health*, 107-114.
- Saemundsen, E., Magnússon, P., Smári, J., & Sigurdardóttir, S. (2003). Autism Diagnostic Interview-Revised and the Childhood Autism Rating Scale: Convergence and

Discrepancy in Diagnosing Autism. *Journal of Autism and Developmental Disorders*, 319-328.

Schubert, C. (2008). Male biological clock possibly linked to autism, other disorders. *Nature Medicine*, 1170.

Schwartz, I. S., & Sandall, S. R. (2010). Is Autism the Disability That Breaks Part C? A Commentary on "Infants and Toddlers With Autism Spectrum Disorder: Early Identification and Early Intervention," by Boyd, Odom, Humphreys, and Sam. *Journal of Early Intervention*, 105-109.

Steyaert, J. G., & De La marche, W. (2008). What's new in autism? *Sprinter*, 1091-1101.

Appendix

Interview Questions

At what age was your child diagnosed with autism?

Before your child was diagnosed with autism what did you know about it? Where did you learn this information from?

Was the school involved with the diagnosing process?

Did your pediatricians' office have information available about autism?

What was your first indication that something might be different with your child?

What has the school offered in order to help support your child?