

**Autism and Its Obstacles**

by

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## **Abstract**

Autism Spectrum disorder (ASD) is a developmental disorder characterized by deficits in communication, adherence to routine, and repetitive behaviors. It is also a condition that is often co-morbid with other medical problems such as intellectual disability or seizures. Current understanding of its prevalence rates in the United States is 1 in 54, with its occurrence in boys being about four times greater than in girls (Maenner et al., 2020). Most people with ASD are found early in childhood, with 72% being diagnosed before the age of eight. These prevalence rates caused the condition to be perceived and understood as a male childhood disorder and treated as such. However, in recent years and in light of new findings, the male bias is being questioned. This also is co-occurring as more adult women are referring themselves to specialists, as they identify with the increasingly available information on the condition. The exact reasons for these variations are unknown, but several ideas have been proposed as to why this disparity exists. Some are based in biological differences found between the sexes, and others in the sociological and historical contexts of autism research. In review of the current state of the literature it is evident that many studies conducted often don't have a significant sample size of girls and women with autism. This gap in the research limits how quickly these children can be identified, especially those without co-morbidities, limiting programs and treatment options that can improve their quality of life.

Autism Spectrum disorder (ASD) is a diverse disorder in presentation and genes associated with its appearance. Its relatively short history as a studied phenomenon, the high rate of co-morbidity with other diseases and conditions, and its perception in the general populace make studying the condition challenging. Challenges encountered are those of diversity, in severity of symptoms, how symptoms present themselves, and co-morbid conditions such as ADHD or seizures. Autism also has a complicated history that has caused much confusion among the general public, who include those most responsible for starting the diagnostic process. However, to understand the shortcomings of the current state of research it must be established what the current scientific understanding of Autism is.

Within psychopathology, it is one of the conditions that has a strong genetic component (Bai et al., 2019). Put simply, if one person in the family has ASD, there are likely others who also have ASD, or at least the genetic markers that have been linked to the presence of ASD. Of course, these markers can be carried by both men and women and passed on to children. However, since there are many genes that contribute to the presentation of autism, identifying a core set has been difficult, and may in fact be impossible since many genes found to be associated with the condition work in tandem to produce the symptoms that are collectively understood as autism (Bhat et al., 2014). This strong genetic component also means that autism isn't developed, however it may go unnoticed for a period of time until situations occur where symptoms become apparent. It also can be that a child may appear to develop neurotypically before demonstrating autistic behavior, and this progression is not preventable.

Symptoms characteristic of autism are deficits in communication and social participation, and repetitive behaviors. Perhaps most noticeable is how people with autism tend to speak. This is in part due to their difficulties with semantics and pragmatics (Ahtam et al., 2020, Kamio &

Toichi, 2000). Meaning that while people with autism understand how a grammatically correct sentence is constructed, they lack the ability to understand abstractions such as metaphors. If one were to say, “It’s raining cats and dogs,” people without autism or neurotypical people would understand it to mean that it is raining very heavily, while a person with autism would understand the phrase literally and become confused at the metaphor. Individuals with autism also have trouble understanding how social context changes the meaning of words and phrases. If asked in a bar, “Do you come here often?” the question in that context has the underlying meaning of flirtation, which a person with autism would miss. They are also generally less invested in topics they aren’t personally interested in, this includes people as well as objects. Repetitive behaviors are best exemplified in behaviors such as stereotypies (stimming, ie hand flapping), echolalia, adherence to routine, ritualistic way of doing things, and extreme interest in particular subjects (American Psychiatric Association, 2017). All of these symptoms range in severity and combinations. Cases are evaluated on level of impairment and the level of support needed so they may function in daily life.

ASD also has a high rate of co-morbidity with other conditions such as intellectual disability, epilepsy and seizures, sleep disorders or disturbances to name a few conditions that aren’t part of core symptoms of ASD (Al-Beltagi, 2021). With many of these co-morbidities having their own genetic markers and environmental influences it makes isolating genetic causes difficult. Autism’s challenges also make it difficult to diagnose co-morbid conditions due to poorer communication and beliefs that autism is all encompassing for all difficulties faced. Physical illnesses aren’t the only illnesses that can occur alongside autism, but mood disorders as well such as anxiety, and depression.

These various co-existing conditions makes the Diagnostic and Statistical Manual (DSM) an invaluable tool for psychologists. The DSM categorize symptoms, and standardize how diagnoses are made. However, this guide is far from being perfected and is currently in its fifth edition. The changes it has undergone since its inception has played a part in confusing psychologists as well as the general public.

### **On the Evolution of the Diagnostic and Statistical Manual**

The Diagnostic and Statistical Manual (DSM) is an organizational and diagnostic tool for mental disorders and illnesses published by the American Psychiatric Association or the APA (*DSM History*). It is used by mental health professionals to diagnose, categorize, and note symptoms of a particular condition. Even given the reliance on it, it is far from being perfect, and is better understood as science's current best understanding of non-typical and/or impairing conditions and behaviors. As new studies are conducted and new information comes to light, the DSM evolves. Various conditions are reevaluated and edited between editions of the DSM.

A brief overview of the evolution starts in 1921 when the American Medical Association's Standard Classified Nomenclature of Disease was first created to help diagnose severely mentally ill inpatients (*DSM History*). This text was later expanded upon after World War II to better understand afflictions of veterans. This expansion was influenced by the sixth edition of the International Statistical Classification of Diseases, which had just added a section specifically for mental illnesses. The resulting text became the first rendition of the DSM. In this edition and the second revision there was a heavy emphasis on personalities and personalities' particular reactions to mental, physical, and environmental factors. DSM-III included more explicit diagnostic criteria as well as a less judgmental perspective on causes of differing mental conditions. It was in the DSM-IV where a concerted effort was made to create modifications to

the text based on new empirical findings. In the most recent edition, the DSM-V, sections were added to give summaries to the state of current research, pointing out where gaps exist. There is also less emphasis on IQ score and greater attention to impact on daily functioning. But pertinent to this paper is some changes made to the classifications of autism between DSM-IV and DSM-V.

Between DSM-V and DSM-IV the conditions under the umbrella of pervasive developmental disorder, most notably: autistic disorder, Asperger's disorder, and pervasive developmental disorders not otherwise specified, were collapsed into one diagnosis of autism spectrum disorder (Harris, 2014). With the collapse came a restructuring in criteria. Instead of the three core domains of the DSM-IV, i.e., impaired social interactions, impaired communications, and restricted and stereotyped behaviors and interests, there are two core domains in DSM-V where impaired social interactions and impaired communication are combined (*DSM IV criteria for diagnosing autistic disorder\**, Harris, 2014).

This collapse also came with a new condition under communications disorders, Social (Pragmatic) Communication disorder (Harris, 2014). Social (pragmatic) Communication disorder is characterized by lacking understanding of situational use of language and implied social rules of communication. The goal of this was to better serve those who may not meet an ASD diagnosis but still suffer from communication issues that impede daily functioning. While this addition has been accepted, the collapse of these three disorders and other pervasive developmental disorders has proven to be a controversial move, not helped by mixed evidence that would either support or contradict the collapse into a spectrum.

Those opposed the collapsing classical autism, Asperger's disorder, and other pervasive developmental disorders (PDDs) into a spectrum are worried about failing to recognize discrete

differences between these conditions (King et al., 2014). Another concern detractors raise is on epidemiological grounds and scientific studies comparing rates, and differences in presentation and level of impact these conditions have on the lives of those living with autism, Asperger's and other PDDs. Within the community of those with Asperger's or Aspies, there are concerns that this shift in portrayal will negatively affect how those similar to themselves will be treated without the connotative label of Asperger's to distinguish themselves from Autism (Chambers et al., 2019). An understandable concern, as most people imagine very different people when told about a person with Asperger's than when told about a person with autism.

Some of those that support the collapse argue that diagnosis is less dependent on defined differences between the criteria for autism and Asperger's than on where one was evaluated (King et al., 2014). That is, the difference between autism and Asperger's was insignificant enough that diagnosis of Asperger's was more dependent on who diagnosed the patient than symptomatology. There has also been no evidence found that there are significantly different responses to the same treatment among those with Asperger's, Autism, or PDDs. It also has been found that repeated evaluations may lead to different diagnoses. This changing of diagnosis suggests that, at the very least, professionals directly working with those with autism aren't clear as to where the distinctions of the subtypes are. In turn, this problem suggests that there is a problem in how these differences are conveyed in the DSM and other diagnostic tools, or that these differences are subjective enough to be influenced by biases (King et al., 2014). One more point supporters raise is how genes found to be associated with the presence of pervasive developmental disorders, such as autism, do not contribute to specific subtypes, but to PDDs generally. With this in mind a new criteria for Autism Spectrum Disorder has been developed, and has been found to be reliable (Harris, 2014).

## **Historical complications**

Shifts in how autism is defined are not without precedent, and this is partly the reason why much of the current research on the condition is full of contradictions and adjustments. An overview of how autism has come to be will help make sense of the changes that the DSM has made, as well as create a context as to where some of the confusions regarding autism started. The history of psychology is a relatively short one, compared to other fields despite its activity, which should not be discounted as part of the reason why there has been much confusion.

Modern psychology is understood to have begun in 1879, with Wilhelm Wundt's Institute for Experimental Psychology as psychology branched off from philosophy (Cherry, 2020, *History of Psychology* 2014). At this point, methods of investigation were mainly self-reports formed during introspection regarding a stimulus. These introspections required trained observers, and controlled stimuli that can be repeated and reproduce the same reaction. While this form of report quickly fell out of practice due to its unreliable nature, it did establish some baseline methods and standards for research. Another key figure to modern psychology was William James and the founding of functionalism, and its use of direct observation. One more key figure of modern psychology is Sigmund Freud who argued for the importance of the unconscious. It was in the context of these developments that the word autism was coined in 1911 by Eugen Bleuler (Evans, 2013).

He first used the term to describe the self-absorption of an infant within the imagination. This self-absorption was considered a normal stage of life, and the persistence of which developed into breaks from reality when concerning realities that were dissatisfactory. This stemmed from the idea that mental illnesses were caused mostly by emotional or psychological factors (Cook and Willmerdinger, 2015). This belief then led to the belief that autism,



schizophrenia and other neurodivergences were caused by parenting styles, for autism it was caused by cold and detached mothers, “refrigerator mothers”. It was this definition of autism that was the basis of schizophrenia. The belief that autism is the self-absorption of one’s imagination eventually shifted, starting in the 1940s with Leo Kanner’s case studies of 11 children, 8 boys, and 3 girls. Each child displayed more typically understood autistic traits of low sociability, strong interests, and desire for routine (Kanner, 1943). Kanner noted that these traits were always present, contrary to schizophrenia, which has a latency period when children develop normally before a change in their behaviors. This discovery was when autism started to be disconnected from schizophrenia.

However, the most significant contributions Kanner’s research (1943) provided may have been the way in which he reported his findings. He kept to more concrete observations of behaviors and information given by parents, rather than trying to interpret the unconscious thought processes of the children he observed. This shift towards more concrete empirical methods for psychological conditions continued with Hans Eysenck and others who argued against Freudian analytic concepts that involved a lot of interpretation of unconscious processes that weren’t directly measured (Evans, 2013). Following this trend, Mildred Creak with several others created a list of key features of schizophrenia in children, as well as strict rules of diagnosis. This format was later used as a model for Victor Lotter to create a new measure for autism, with greater focus on behavior and developmental deviations than the thought processes of children. This shift towards quantitative evidence also caused the identification of hallucinations, a hallmark of schizophrenia but not autism, much harder to ascertain without direct communication from the child, and further distinguished autism from schizophrenia during the 1960s. Schizophrenia was becoming characterized by hallucinations. While autism was

becoming a condition on its own, characterized by low sociability, adherence to routine, and impoverished linguistic skills. This separation went so far as to completely exclude hallucinations and schizophrenia as a possible co-morbidity (Evans, 2013).

However, it wasn't until the 1980s that autism would be understood as a communication issue rather than a relational or emotional one, with Lorna Wing and Judith Gould's push to put several conditions under the conception of developmental disorders (Evans, 2013). It was also Wing and Gould who conceived of these developmental deficits as a spectrum and related. Now the next big shift in understanding autism is in the prevalence and presentation of women and girls who going all the way back to Kanner's 11 case studies were skewed male. This is in light of more adult women referring themselves for diagnosis, and a scientific realization of an area severely lacking vigorous research.

### **Modern Complications**

It should be known that there will likely always be a male bias in the prevalence of autism, as some genes on the X chromosome have been identified to be linked to the presence of ASD (Bhat et al., 2014). A 'female protective effect' has also been found (Werling & Geschwind, 2013). Meaning that it takes more risk factors for a girl to present with autism than it would a boy. However, recent research suggests that the often-cited rate of four to one to be an overestimate in favor of males (Werling & Geschwind, 2013). The true ratio is yet unknown, but a meta-analysis in 2017 has suggested a three to one being likely the closest to true prevalence rates, at least among individuals between the ages 0 to 18 (Loomes et al., 2017). Yet, it should be noted that using prevalence data among the most severely impaired that the gender ratio is closer to two to one, especially if co-morbid with an intellectual disability (Werling & Geschwind,

2013). Being co-morbid with an intellectual disability drastically increases the likelihood of women and girls being diagnosed.

One of the possible explanations for why there is a sex bias in rates of diagnosis is the social perceptions of gender and that certain behaviors and actions are more permitted than others for certain genders (Blair et al., 2019). Since autism is mainly flagged by parents and teachers, who often aren't experts nor are always up to date with current literature, they are susceptible to falling on old notions and stereotypes when identifying potential cases of autism. With the historical records being greatly biased towards males, such as in Kanner's (1943) case studies, many of the observed traits such as extreme interests also have a bias toward stereotypically male interests such as trains. This primes parents, teachers, and doctors to look for autistic traits in boys, and in stereotypically male interests. This priming is possibly making it easier to overlook girls, not just because people believe girls aren't affected, but because the extreme interests girls have tend to differ from those commonly recognized. For example, a girl with autism may have an extreme interest in dolls, an acceptable interest for the stereotypical girl to have. The priming towards boys and stereotypically male interests may lead parents and teachers to overlook subtler manners, such as how the girls with autism play with the dolls. Another possibility, though unproven, is that girls may have extreme interests, but ones that come and go in phases (Kanner, 1943). This is described to be the case for Barbra in Kanner's 5<sup>th</sup> case, "[she] gets stuck on an idea, game, etc., and rides it hard, then goes to something else..." (1943). The common understanding is that restricted interests are lifelong. If it is that girls are more likely to have intense interests that change over a lifetime, it clashes with popular conceptions, leading to dismissing the possibility of autism as the reason for their intense interests. But this possibility must be investigated further as current research is lacking.

Other preconceptions can also lead to people overlooking more subtle symptoms, such as the stereotype of obsessive girls, but also the assumption of an asocial nature of individuals with autism. Females with autism tend to be more social than boys with autism, though they both lack interpersonal skills inherent in neurotypical individuals. Both biological and social reasons have been proposed to explain why girls with autism interact with peers more. One possible biological reason why girls with autism may interact more with peers is that the female brain is inherently more interested in socializing due to differences in how they react to different levels of neurotransmitters (Borland et al., 2018).

The social reason is that girls are expected and thus pressured to be more social due to societal norms. Whatever the case may be, it is also permissible for girls to be quiet or shy, enabling confused girls the time to learn scripts of interaction without understanding the meaning behind the interaction (Blair et al., 2019). This behavior and others that also work to conceal difficulties has been commonly self-reported by diagnosed women as a social strategy and is described within the community as masking. At the same time, scientific studies investigating masking find its occurrence within male populations significantly less, and subsequently the awareness of these social techniques is relatively low to non-existent outside of the community and scientific understanding (Lai et al., 2016). Even within these communities, these coping techniques are only recently garnering attention. The recent draw of attention to this social camouflaging also reveals another fundamental flaw in lay people's understanding of the condition, that autism is apparent in unconcealed external symptoms. Behaviors that are immediately alarming such as head banging, tantrums due to small changes, and delayed or nonexistent linguistic skills. While many of these commonly understood behaviors are present in both sexes, not all of them are present in all individuals, or are expressed in non-apparent ways.

A child with autism interested in social relationships may force themselves not to self-stimulate (i.e. hand flap) or stim in less socially disrupting ways (i.e. leg bouncing).

### **General Knowledge on People with Autism**

One more layer to complicate this condition as well as many other mental health issues is the general public, and a lack of knowledge. The complicated history previously stated has created a confusing set of facts for the public. When the public first started hearing about autism in the 1940s and 50s its presence was attributed to parents, particularly mothers, being detached from the child. While this “refrigerator mother” theory was challenged within scientific circles, media at the time perpetuated the idea. It wasn’t until much later in the early 2000s that a new alarmist idea came to the fore with Andrew Wakefield’s paper suggesting that the MMR vaccine was linked to the presence of autism.

For autism and much of scientific understanding the saying, “A lie travels around the globe while the truth is putting on its shoes,” is painfully true. What is left out in the quote is also the fact that sometimes the lie is far more convenient and/or more attractive than the truth. An example are anti-vaxxers who are trying to spread their idea. The reasons why they wish to spread their ideas may range from wanting to help others avoid harm, to wanting to promote alternative health products. The lie that vaccines cause autism is simply convenient for them and likely feeds into other narratives they may hold in regard to science and suspicion of authority. Beyond anti-vaxxers is the news media. Controversial headlines such as ‘Are vaccines causing Autism’ grabs people’s attention, but even if the question is proven false the question itself casts doubt. Part of the cause is because of the hopeful message it broadcasts, that autism is preventable, and your child can live a normal life if only you avoid doing this. But as the truth

became far more widespread news coverage on autism has receded into the background, leaving mixed and vague information about the condition.

The opacity of information on autism, along with misinformation created an environment where the general public are uncertain what is true about people with autism. It has also allowed for many myths to arise without much information to make decisive conclusions. Myths such as that people with autism also have savant skills, lack emotions, are always male, and dislike socializing (John et al., 2017). Savant skills, or skills exceeding capabilities normally expected for the person are very rare, but through over representations in media has become commonly associated with autism. This likely because like the vaccine narrative, it creates an interesting story that has a hopeful message, 'even if they are lacking in a lot of other skills, they are gifted in this one'. In truth only about 10% of individuals with autism also have savant skills (Bhat et al., 2014). Most imagine people with autism as someone who does not relate to others and are overall disinterested in social relationships (John et al., 2017). Coupled with their challenges in communicating, especially in non-verbal forms, as well as difficulties in identifying emotions it is easy to assume that people with autism lack emotions. This is not true. People with autism have a normal range of emotions, but may have trouble identifying them both in others and within themselves. It is true that many people with autism tend to avoid social situations for various reasons, such as genuine disinterest, but also discomfort and confusion (Guy-Evans, 2022, Deweerdt, 2017). For the myths that only boys can have autism, and that they dislike socializing comes from what little the public knows about autism. Most of science has been focused on autism in males and generally emphasis the male skew. With little information or publicity of woman having autism it becomes easy to assume that women cannot be born with autism. Most of the lay public also knows that individuals with autism tend to have poorer

communication skills, however it is unknown the reasons behind these challenges. In John's (2017) focus groups participants proposed a few possible reasons from being disinterested to introversion, but both ideas were questioned during the session. In fact, many of these myths are held with doubt, as are the facts. The confusion is likely due to the lack of scientific literacy, poor media portrayals, and lack of firsthand contact.

Unfortunately becoming scientifically literate is an investment of time and resources that rarely, if ever pays out for the average person. The best route to increase literacy would be to make it a requirement within school. Barring that, journalists would need to become literate and carefully inform the public on changes, why the changes happen, as well as the limits the research have in explaining phenomenon. They would have to become keenly aware of their pivotal role in informing the public and be certain in their research. The same can be said for writers, and directors who want to feature people with autism in their stories. They must write with consideration to the differences, difficulties, and advantages those with autism have not just in comparison to most people, but to other individuals with autism.

### **What is Known About Women and Girls with Autism**

With all these considerations of how the current understanding of autism was produced it is little wonder that in-depth studies into women and girls with autism is lagging. What is known about women and girls with autism is that they will often hide their deficits using several techniques collectively called camouflaging. They are also more likely to be diagnosed with anxiety, depression, or eating disorders before autism, and are prone to sexual abuse (Rynkiewicz et al., 2019). Some of the main departures from understood behavior in men with autism is that woman with autism tend to have stronger social interests and are skilled at observing and mimicking normal social behavior. Another difference between woman and men

with autism is the general age they are diagnosed. Men tend to be diagnosed quickly during childhood, whereas many higher functioning women are either not diagnosed or are diagnosed much later when social skills required exceeds their ability to camouflage. Typically, this is during adolescence, but can be delayed until adulthood (Blair et al., 2019). Diagnosis often requires significant self-advocacy as they often meet push back by service providers who doubt women can have autism. This belief creates a feedback loop that maintains the four to one ratio of male to female. Service providers and doctors are less likely to consider the possibility of autism in women, so when prevalence studies are done relying on previous diagnosis the results are close to the four to one ratio in favor of males (Blair et al., 2019, Werling & Geschwind, 2013). The exception is in lower functioning groups where symptoms are more obvious that this ratio tends to drop to three or two to one in favor of males.

Less clear distinctions are on exactly how females with autism present overall in ways that can be measured and be used to better diagnose girls earlier. It has been proposed, that like with the general population, that girls would have fewer external symptoms such as inattentiveness and aggression and more internal symptoms such as depression and anxiety, but contradictory results have been found (Mayes et al., 2020, Werling & Geschwind, 2013). It should, however, be noted that these results are from childhood and adolescents, and mainly through parent report. Far fewer studies have been conducted with adults with autism. Another symptom examined with contradictory results is regarding the severity that girls and women with autism experience restricted and repetitive behaviors (Mandy et al., 2011, Mayes et al., 2020). Considering the mixed of evidence for sex-based differences in symptom severity, it may be that the measures that are being used, parent and teacher surveys, are flawed. These flaws may be in respect to gender biases parents and teachers hold.



These gender norms create certain and differing expectations for boys and girls. A quiet boy may catch the attention of a parent or teacher while a quiet girl is accepted as normal. These assumptions are made unconsciously. And as stated before this can create opportunities for girls with autism to go unnoticed. It should also be noted that the wide levels of severity, and particular symptoms a person with autism may exhibit further complicates what is identified by a parent or teacher.

## **Conclusion**

Taking in our current understanding of autism, it is clear that there are a lot of questions left to be answered. Fundamental questions regarding how psychological research is conducted, weighted, and the reliability of previous assumptions. Considering the youth of the field it is no surprise that there are flaws in current methodological approaches, most notable in many of the studies found during research for this paper was the reliance on previous diagnosis for inclusion criteria. With an unknown number of girls simply being overlooked by teachers and parents as possibility having autism due to current conception, reliance on previous diagnosis for prevalence studies or studies investigating sexual differences is unreliable. This is subject to change as more teachers, parents, and doctors consider the possibility of autism in girls. It also throws a question over many studies that have been performed with the four to one ratio in mind, making it likely necessary to reconduct those studies with larger simple sizes of females with autism. This is not to suggest that the data gathered from those studies are invalid but to be understood with a possible male skew in mind.

The main source of this bias is partly biological, as all prevalence studies conducted and Loomes's (2017) meta-analysis have concluded that there is an unknown degree of biological resilience that females possess that males do not, the female protective effect. But for biases

found to be in greater effects of three perhaps even two to one ratios assumptions, sociological and cultural factors should be considered. Unfortunately, most of the studies used for this paper used a majority culturally western groups of people. So, it is only speculation how different cultural standards for women would affect women and girls with autism appear. The effects seen would be based in broader understanding of differing mental capacities, as well how such capacities are handled. For instance, Kim (2012) offers two examples of cultural values influence autism diagnosis and reaction therein. In cultures that are deeply ashamed of such differences such as Korea, there is deep humiliation for the mother of a child born with autism. In places where disability is less distinguished and personhood paramount, such as Nicaragua, there is a much greater passive acceptance and a great desire to give aid. However, with the data that has been gathered it is clear that whatever changes happen to the criteria for diagnosis greater awareness of the possibility of women and girls having autism is not remote.

This awareness must not just be spread within the scientific community, but to the general public as well. This is because of the nature of how autism especially in childhood is found early, through the knowledge of doctors, teachers, and parents. The knowledge of these groups is vitally important in detecting the idiosyncrasies and providing support that can drastically improve prospects. Another important group to inform are journalist, writers and directors who play a major role in forming the collective narrative of individuals with autism who do not have firsthand experience with this group of people.

Lastly it is clear that there are gaps in the research, especially regarding adults with autism, and those able to articulate their own thoughts. Future research should seek to ask qualitative questions and gather quantitative data from this group. The data gathered will likely

point to new avenues of research to better identify girls who are slipping past the current diagnostic process.

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