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BENEFITS AND DRAWBACKS OF AN AUTISM DIAGNOSIS

SYDNEY CHIAT
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Reviewed and approved* by the following:

Dr. Amy Crosson
Assistant Professor of Education
Thesis Supervisor

Dr. Paul Riccomini
Associate Professor of Education
Honors Adviser

* Electronic approvals are on file.

ABSTRACT

The goal of this thesis is to investigate the benefits and drawbacks of receiving an Autism Spectrum Disorder (ASD) diagnosis. Through an instrumental single case study of an eight-year-old male, structured interviews were conducted with his parents, his older sister, his current special education teacher, and a past tutor. Structured interviews were conducted both through a) providing interview protocol questions by email to which participants provided written responses; and b) Zoom video conferencing using an interview protocol. The Zoom interviews were recorded and later transcribed. In addition, notes from a series of tutoring sessions with the child (in the form of researcher memos) were also included as a data source. Participants were asked to describe personal experiences with ASD and respond to specific questions on the impacts of a diagnosis itself. The written (email) and transcribed responses were then coded using a scheme based on major themes that emerged from analyzing the data and that were grounded in previous research. After analyzing the data, I found that there were both benefits and drawbacks to receiving an ASD diagnosis. Benefits included better instruction and services for the child. Drawbacks included a sense of being stigmatized as well as a sense of burden on family members. Further research is needed to understand how to minimize or mitigate the drawbacks of an ASD diagnosis.

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Introduction

According to the Centers for Disease Control and Prevention, Autism Spectrum Disorder (ASD) can be defined as “a developmental disability that can cause significant social, communication and behavioral challenges,” (2021). ASD is a spectrum, meaning the signs and symptoms of this disorder can vary from person to person. The National Institution of Mental Health explains the spectrum by saying “Autism is known as a ‘spectrum’ disorder because there is wide variation in the type and severity of symptoms people experience. ASD occurs in all ethnic, racial, and economic groups,” (2018). Although ASD can occur in any child, with the rate being one in 44 children (Centers for Disease Control and Prevention, 2021), the Autism and Developmental Disabilities Monitoring (ADDM) Network found that boys are more than four times more likely to be diagnosed with ASD compared to girls (2021).

Since the year 2000, autism rates have slowly increased by about 20 children every two years. This means more and more children are getting diagnosed with ASD every year in the United States. This increase may be attributed to the changes conditions of ASD diagnoses. (Centers for Disease Control and Prevention, 2021).

Receiving an ASD diagnosis may lead to many benefits for families. However, there are some potential drawbacks. The purpose of this thesis is to understand the nature of these benefits and drawbacks from multiple perspectives. My goal is to provide a grounded and highly contextualized case study of a single case of a child with ASD.

First, I will explain the most recent research in relation to ASD and the benefits and drawbacks a diagnosis may entail. In the subsequent section, I describe different approaches to special education. Next, I explain the methodology of interviews I conducted and results that

came from the study. Finally, in the discussion I will discuss my findings and relate the interviews back to the literature.

Literature Review

How does a child get diagnosed with autism? How long does it take? What is the process like?

ASD is a disorder that is quite difficult to diagnose. There is no specific test to get a diagnosis. Instead, doctors look at the child's behavior patterns and developmental milestones to aid them in their diagnosis. A diagnosis can be made as early as 18 months with age two being considered reliable (Centers for Disease Control and Prevention, 2021). However, “the average age at diagnosis continues to be between 4 and 7 years,” (Mazurek, 2018). The process of getting a diagnosis starts with parents' concern and then, on average, takes about three years to officially diagnose (Mazurek, 2018).

Upon regular check-ups with the pediatrician, the health care team will complete a developmental monitoring questionnaire and simply observe the child to see which milestones have/have not been met. Note, there are times when a screening will be completed even without concern. These check-ups occur at ages 9, 18, and 30 months. If there are areas for concern, the doctor will move onto a developmental screening. Autism developmental screenings occur at 18 and 24 months (Centers for Disease Control and Prevention, 2021). Parents often see the first signs of autism such as avoiding eye contact and speech delays. Pediatricians will also begin to monitor developmental milestones and note if there is an area of concern (Centers for Disease Control and Prevention, 2021).

Jacobs et al. (2018) conducted one-on-one interviews with 16 physicians who work to diagnose children with autism. The physicians interviewed “found it difficult to assign a diagnosis to a child and to explain it sufficiently well to his/her parent.” Moreover, the

interviews also concluded that “the ASD diagnosis had a dual effect on parents: the parents were devastated and yet relieved” (Jacobs et al., 2018).

What are the approaches to educational instruction for children with an autism diagnosis?

Iovannone et al. (2003) began to examine effective educational practices for students with ASD. They found six core themes that should be included in effective educational practices:

1. individualized support and services for students and families;
2. systematic instruction;
3. comprehensible and/or structured environments;
4. specialized curriculum content;
5. a functional approach to problem behaviors; and
6. family involvement.

In addition to these core themes, the Individuals with Disability Act calls for students with ASD to be placed in the least restrictive environment (LRE). The LRE is determined on a case-by-case basis by the student's individualized education program (IEP) team, which is a group of professionals and the student's parents.

Below, I explain the diverse instructional settings in which children with ASD may be placed, depending in large part on the child's IEP. Each of the following placements for students with autism have all six of Iovannone et al.'s (2003) core themes embodied into their curriculum.

General education classroom. In this placement, students with ASD receive all their instruction in a general education classroom. Their instructor is a general education teacher. Accommodations can be given, as stated in the IEP, but instruction is supported with materials and modifications that may be given by the special education teacher. The special education

teacher may come into the general education classroom and work with the student and a couple peers as well (Vanderbilt's Iris Center, n.d.).

Special education pull-out. For this placement, students spend most of the day in the general education classroom, but may be pulled out to a resource room for individual or small group instruction with the special education teacher. Both the general education teacher and special education teacher collaborate in this placement (Vanderbilt's Iris Center, n.d.).

Self-contained classroom. In this placement, the student will spend much of their time in the special education room. Students in this classroom have different types of disability and needs. This classroom is usually much smaller in size and has a smaller student to teacher ratio. Some activities (i.e., PE, Art, etc.) may be integrated with a general education classroom (Vanderbilt's Iris Center, n.d.).

Special schools. In this placement, the entire school is a specialized school. All staff at this school have background knowledge on disability and have the resources, education, and accommodations needed to support the students (Vanderbilt's Iris Center, n.d.).

Residential facility. Students with a more severe disability may need constant care, so a place with nurses, aids, and educators are best suited for them. In this placement, the students live at the facility (Vanderbilt's Iris Center, n.d.).

What are some potential benefits of receiving an autism diagnosis?

Oftentimes, parents begin to blame themselves for what their child is going through. With a diagnosis, a practical and medical reason is given to both the child and the families. The diagnosis also validates the parents' feelings.

For example, in a study with sixteen physicians who worked closely with young children with an ASD diagnosis, Jacobs et al. (2018) found that “ASD is perceived by physicians as a useful and valuable diagnosis both because of treatment related consequences and of several psycho-relational implications” In addition, a diagnosis can give parents a sense of closure, which seems to help parents understand that they do not have to “blame themselves” (Jacobs et al., 2018).

Not only does a diagnosis provide psychological relief for some parents, but also a diagnosis can open doors for the child. The Individuals with Disabilities Act (IDEA) clearly states that all children with disabilities have the right to free and appropriate education and appropriate services as needed. However, to benefit from the mandates associated with IDEA, a diagnosis is needed. One of the biggest benefits of receiving a diagnosis is the fact that the child gains access to services that they may not have had before (United States Department of Education, 2020). Services can include but are not limited to occupational therapy, speech therapy, academic help, etc. Without the diagnosis, students with autism would not be able to receive the services they need.

The American Psychological Association explains more about IDEA saying it “provides financial support for state and local school districts.” Elizabeth Gross (2003) furthers this research by looking at services provided by IDEA. Some of the resources include but are not limited to: family training, psychological services, social work services, even help with costs that are “necessary to enable an infant or toddler and the infant’s or toddler’s family to receive services” (Gross, 2003).

What are some of the drawbacks of receiving an autism diagnosis?

As amazing as these services can be, prior scholarship has revealed that there are also potential negative implications to receiving an autism diagnosis. An autism diagnosis does not only affect the child but may affect the family as well. For example, Pertucilli et al. (2021) investigated perspectives of parents of children with autism. Through focus groups and semi-structured interviews, the investigators found “relational strain among family members ... as well as cultural understandings of child development and child-rearing practices,” along with “reported loss of income due to time off from work” (Pertucilli et al., 2021). Families may feel a burden to aid their autistic child which may, in turn, result in less focus on other children in the family.

In their summary of research on the sibling of an individual with an ASD diagnosis, Ferraioli and Harris (2010) found that “the child's understanding of ASD depends in large part on her or his level of cognitive development”. In the early ages – ages PreK to six, “siblings are generally unable to form a clear picture of ASD,” yet, they may start to “realize that something is different about their sibling with a disability” (Ferraioli & Harris, 2010). Once the siblings reach ages seven to 11, “they can identify the constellation of deficits associated with autism and comprehend the cognitive and social implications of having a diagnosis” (Ferraioli & Harris, 2010). They also may start feeling a sense of serving as “protector” over their autistic sibling. Their lives start to revolve around their social life, and they see that their autistic sibling may not have a life like this.

As for the child who receives a diagnosis, previous scholarship has investigated how a “stigma” forms around them the instant the diagnosis is given. These may be stereotypes that the child will need to live with the rest of their life, as well as obstacles to overcome. For example, Thompson-Hodgetts et al. (2020) explored this concept by performing a scoping review on 37

articles that met their criteria. They concluded that “children with autism are at high risk of experiencing social exclusion and bullying at school, even with the increased emphasis on inclusive education” (2020).

Kinnear et. al. (2016), performed similar research but with a focus on family reactions to a diagnosis. In their findings, they found that 95% of the parents surveyed think that their child with ASD has been stigmatized. Further, they found that the parents themselves begin seeing life as harder once their child is diagnosed.

Research Question and Purpose of this Thesis

Taken together, previous research has suggested that receiving an autism diagnosis can be both beneficial and difficult. Individuals may fear disclosing their diagnosis with fear of being judged and/or stigmatized (Thomspon-Hodgetts et al., 2020). However, in some cases, “the positive implications of the diagnosis outweigh the negative ones” (Jacobs et al., 2018). In this thesis, I address the following research question: What are the benefits and drawbacks of receiving an autism diagnosis? I explore this question from the perspective of parents with a child who has an ASD diagnosis, the sister of the child, and two educators of the child. Through these perspectives, I hoped to further gain an understanding of the spectrum of feelings and experiences associated with a child receiving an ASD diagnosis.

Methodology

For this research, I conducted an instrumental, single case research study (Barone, 2011). The focal child who was diagnosed with ASD is Patrick Miller (pseudonym). In addition to Patrick, there were five other participants in the study: two parents of the child, the child's teacher, the sister of the child, and the child's personal tutor (thesis author). Data sources were Zoom video interviews, written responses to interview questions submitted by email, and notes (reflection memos) written by the tutor (thesis author) from teaching sessions with the child. The names used for the parents, the teacher, the sister, and the child are all pseudonyms. The study consisted of choosing a willing family to disclose their experience, and then work with the family to seek out others that the child had past relations with.

Participants

I met the Miller family in the summer of 2020 when I put an advertisement for summer tutoring on our community page. I tutored Patrick in reading and writing during the summer. Patrick was 6 at the time, now 7. He was diagnosed with ASD when he was 3 years old. Patrick is a 7-year-old boy who lives in a suburban area. Patrick and his family are all white. Patrick is in Mrs. Lewis' special education classroom. Patrick's sister, Violet, is currently in seventh grade in a general education classroom. Mr. and Mrs. Miller, Bob and Helen respectively, also agreed to be interviewed. See Table 1 for information on the data collected from each participant.

Table 1. Study Participants, their Relation to Focal Child, and Data Source for Each Participant

Participant	Relation (Role)	Data Source
Patrick Miller	Child with ASD	N/A

Violet Miller	Older sister of Patrick	Zoom Interview
Bob and Helen Miller	Parents of Patrick	1 st Interview – Written Response 2 nd Interview – Zoom Interview
Mrs. Lewis	Patrick’s current teacher	Written Response
Sydney Chiat	Patrick’s Tutor in summer of 2020	Written Response

Table 2. Interview Participants, instructions given for interview, and the questions asked

Participant	Instructions Given	Questions Asked
Mr. and Mrs. Miller	“To the best of your ability, please answer these questions. I do not need full sentences. Just simple bullet points of your answers are fine.”	First Interview: 1. Can you tell me about how Patrick was first diagnosed? What was the experience like for you? 2. What did you see in Patrick that made you infer he may have autism? What prompted you to seek an evaluation and what were you thinking during the time?

3. How did you learn about autism? How has your understanding of autism changed?
4. In what ways do you think having a diagnosis has helped Patrick In what ways has this not been helpful to Patrick?
5. How does Patrick's diagnosis affect you or anyone in your family?
6. What do you think people misunderstand about autism?
7. Do you think that there is a stigma around children with autism?
8. Anything else you want to tell me?

Second Interview:

1. Have you and Bob thought about telling Patrick that he has a diagnosis? (Or have you or Bob specifically told him?) In what ways do you think it might be helpful or unhelpful to Patrick to be told that has Autism?
2. What is one thing you wish people would understand about autism?

		<ol style="list-style-type: none"> 3. You talked a lot about the drawbacks of the diagnosis (relationships, social life, etc.), what do you think some benefits are?
Sydney Chiat	<p>“To the best of your ability, please answer these questions. I do not need full sentences. Just simple bullet points of your answers are fine.”</p>	<ol style="list-style-type: none"> 1. What made you choose to go into special education? 2. Do you think that there is a stigma around children with autism? 3. What are the pros of receiving a diagnosis? What are the cons? 4. What is it like working with a child with autism?
Violet	<p>“To the best of your ability, please answer these questions. I do not need full sentences. Just simple bullet points of your answers are fine.”</p>	<ol style="list-style-type: none"> 1. What is it like for you to have a brother with autism? Do your friends/peers treat him or you differently? Do you feel like Patrick has gotten more help since he has received his diagnosis? 2. Do you ever feel like you don't get attention because of his diagnosis? 3. Is there anything else you want to tell me?

Mrs. Lewis	<p>“To the best of your ability, please answer these questions. I do not need full sentences. Just simple bullet points of your answers are fine.”</p>	<ol style="list-style-type: none"> 1. What made you choose to go into special education? 2. For children who have a diagnosis of ASD, what is your role in the diagnosis process? How is the process of seeing someone going through an ASD diagnosis? 3. For your students who are diagnosed as “autistic,” what are the pros of receiving a diagnosis? 4. What are the cons? 5. Do you think we are over diagnosing? under? 6. If you could change 1-2 things about the way we provide education for children with autism, what would you change? Why?
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Interview Protocol

The interview was designed to further understand different perspectives of the participants and their own relation to how they experience an autism diagnosis. The full protocol appears in Table 2.

Analytic procedure. Now, the second phase of this study consisted of transcribing the Zoom interviews. I recorded the interviews so that I could go back and watch the interview over

again. During my first interaction with the recording, I took note of the quotes I found relevant to the scholarly articles I had previously found. For example, both Mrs. Lewis and Kinnear et al. (2016) discussed the stigmas that come along with a diagnosis. As I was transcribing, I applied qualitative open coding to identify themes related to benefits and drawbacks of diagnosing a child with ASD. Classifying the data into these descriptive codes helps the researcher identify common characteristics and to group the data into themes (Khandkar, nd). I began to highlight quotes from the transcribed and written responses, and the memos, that fit each code. Through this coding process, four major themes from the interviews began to emerge:

- Theme 1: Flexibility
- Theme 2: Stigmas
- Theme 3: Opportunities
- Theme 4: Constants

Results

As a result of analyzing the data sources for this study, I found the following major themes: *flexibility*, *stigmas*, *opportunities*, and *constants*. For each of these themes, I took into consideration each participant and their answers to the interview questions.

Flexibility

Throughout the data, I found multiple connections of ‘flexibility’ threaded in the interview answers and researcher notes. Specifically, Helen said, “I try to read as much as I can, especially about the perspective of people with autism and how they feel and what they want ... so anything I can learn about an autistic perspective, I am in” (Interview 1) In Helen’s answer, one can see the constant need to be flexible when learning and connecting with someone with autism.

Something I experienced when tutoring Patrick was the need to be flexible in teaching. Just as with any student, he had days where he was easily distracted and days where he was focused and on task. Being flexible was one of the biggest lessons I learned as certain tactics for teaching may work one day, but the next may not work at all, “so finding what works and adapting to them is the best practice I have found.” Being flexible and adaptable is a quintessential idea for those who interact with the child.

Violet also mentioned this throughout her answers. For example, she explained, “I want people to know it [autism] is so wide and a big variety” (Zoom Interview). Flexibility does not just mean being flexible with the person with autism, but even with the concept of autism itself. “Everyone with autism is so different, people think it’s so one note and they are so wrong” (Zoom Interview). Therefore, flexibility plays a large part in interacting with someone with ASD.

Constants

When talking to the Miller family, they all kept making one thing very clear: the diagnosis did not change Patrick. Both pre- and post-diagnosis, Patrick had ASD. Bob and Helen said, “He has always had autism, we are a family with autism, open about it, joke about, live our lives very openly about it. There will never be a moment where I think we must tell him. It’s who we are, no big secret” (Interview). Violet agreed when I asked her what she thought. She was quite short with her answer: “I never viewed him as autistic, just Patrick” (Zoom Interview). A diagnosis does not change the person. The Millers treated Patrick the same pre and post-diagnosis, because he was the same person.

Stigmas

From the perspective of Patrick’s parents, Helen and Bob noted that there would be, “a harder path for Patrick and that we could not afford to hope for a future that we would not know what he would be capable of achieving” (Interview). These stigmas not only affect the person with the diagnosis, but the family members around them as well. Helen often mentioned the impact it has had on Violet, lamenting that, “siblings make the biggest sacrifice because they are just kids and have to compromise more than I would hope for them. Less social events, less playdates” (Interview).

However, when asking Violet about her brother, she said she wouldn’t want it any other way. She sees the way people look at him and pity him. Violet said that this has made her a stronger person, learning to advocate for herself and Patrick. Just as the family members are affected, teachers constantly must see the stereotypes being upheld at school and navigate how to help their students and educate their peers.

Mrs. Lewis said, “the label has a stigma with it” (Interview 1). She said that there are obvious “struggles and hardship some families face...fear in parents that their child will miss out on milestones and social interactions and relationships” (Interview 1). This further validates Kinnear et. al.’s (2016) findings as well.

Looking at my own answers, I wrote something similar, “I think there is a misconception that students with ASD have certain characteristics, i.e., not good at eye contact, not loving, unable to talk, etc” (Interview 1). Often, this leads to children with ASD to not have many friends or social interactions.

Opportunities

Mrs. Lewis explained the opportunities she has seen after her own students have received “speech language therapy, occupational therapy, ABA therapy, and an IEP. Having the IEP in place is the most important in my opinion as that can determine how their specific needs can be met in the school environment. It lays out their accommodations and or modifications to the way their academics are delivered.” Coming from the educational perspective these services aren’t available without the diagnosis.

The Millers mentioned the opportunities that Patrick was also given after receiving a diagnosis. “You get to put a stamp on someone’s head that says ‘autism’ and boom, services. You can get them the help because sometimes you can’t help them.” The feeling of understanding and knowing that your child will be understood is something both Helen and Bob continually talked about.

Discussion

Aligning with findings from Thompson-Hodgetts et al. (2020), each participant noted stigmas that surround an ASD diagnosis. Both myself and Mrs. Lewis mentioned the stigmas in the classroom and schools we see and how they are played out with peers. The Millers also talked about the fear of getting the diagnosis because of the stigma. The Millers also explained how the grandparents were the most distraught because of the stigmas and stereotypes that come with the diagnosis. Both of Patrick's grandmothers have been employed in school districts and they had seen the stigmas firsthand. They didn't want this for their grandchild. The bullying that Thompson-Hodgetts et al. (2020) talked about was also noted in all three interviews.

The bulk of Mrs. Lewis' answers to questions about benefits had to do with the opportunities a diagnosis can lead to, just as Jacobs et. al. (2018) found. However, Mrs. Lewis was not the only one to notice these benefits. The Millers talked about the services that became available when Patrick was diagnosed and how much easier it was to get him the services. Thankfully, the Millers could afford these services beforehand. However, with a diagnosis, more and more opportunities became available.

Both themes of flexibility and the constants were not found within my research.

As for the limitations of my study, I think I could have looked at another big variable: cost. A lot of times, the road to the diagnosis costs a lot, so families who are struggling do not get the tools they need. As the Miller's noted, they were financially able to get Patrick therapy and other services before the diagnosis was given. They could even afford to take him to the specialists to get the diagnosis. Mrs. Miller kept noting the people who don't have this luck. These variables of cost and available services would be another characteristic to look at when doing further research.

I think it also would have been interesting to interview multiple special educators and see the different perspectives they have. Special educators in public schools may have a different perspective than those in residential programs. I think the age of the special educator could also affect how they go about their teaching and view their students. Teaching practices have been constantly evolving.

Additionally, this was only one family's story. As mentioned throughout the paper, meeting a child with autism only means you have met one child with autism. This paper is specific to the Miller family and may not be experienced by every family. To further this research, more families need to be interviewed so that there is a clear and consistent understanding.

Lastly, not being able to see the interviewees in person also made it difficult. In a typical interview setting, I would have had the chance to ask follow-up questions right away and really see the physical emotions of the interviewees. Having the written response also gave the interviewees some time to think about their answers. This can be good, but it would have been interesting to get the initial reaction to the question.

My biggest takeaway from this study is trying to be understanding of the labels and stigmas that surround ASD. As a special educator, it is engraved in my brain that a disability does not define a person, but we are all not there yet. This study helped me remember to consider others' perspectives and experiences when it comes to a diagnosis and the impact it may have on not just the child, but the family.

BIBLIOGRAPHY

- APA. (2022). *Individuals with disabilities education act (IDEA)*. American Psychological Association. Retrieved January 27, 2022, from <https://www.apa.org/advocacy/education/idea#:~:text=The%20Individuals%20with%20Disabilities%20Education,education%2C%20employment%20and%20independent%20living>
- Barone, D. (2011). Case study research. In N. Duke & M. Mallette (Eds.), *Literacy research methods* (pp. 7-28) (2nd ed.). New York: Guilford Press.
- Centers for Disease Control and Prevention. (2021, April 19). *Autism spectrum disorder (ASD)*. Centers for Disease Control and Prevention. Retrieved September 27, 2021, from <https://www.cdc.gov/ncbddd/autism/index.html>.
- Ferraioli, S. J., & Harris, S. L. (2010). The impact of autism on siblings. *Social Work in Mental Health*, 8(1), 41-53. doi:http://dx.doi.org/10.1080/15332980902932409
- Gross, E. (2003). *A family impact analysis of the Individuals with Disabilities Act, Part C: Infants and Toddlers with Disabilities*. (Family Impact Analysis Series). Madison, WI: Policy Institute for Family Impact Seminars.
- Iovannone, R., Dunlap, G., Huber, H., & Kincaid, D. (2003). Effective Educational Practices for Students With Autism Spectrum Disorders. *Focus on Autism and Other Developmental Disabilities*, 18(3), 150–165. <https://doi.org/10.1177/10883576030180030301>
- Jacobs, D., Steyaert, J., Dierickx, K., & Hens, K. (2018). Implications of an autism spectrum disorder diagnosis: an interview study of how physicians experience the diagnosis in a young child. *Journal of clinical medicine*, 7(10), 348.
- Kinnear, S. H., Link, B. G., Ballan, M. S., & Fischbach, R. L. (2016). Understanding the

experience of stigma for parents of children with autism spectrum disorder and the role stigma plays in families' lives. *Journal of Autism and Developmental Disorders*, 46(3), 942-953.

Mazurek, M. O., Curran, A., Burnette, C., & Sohl, K. (2018). ECHO Autism STAT: Accelerating

Early Access to Autism Diagnosis. *Journal of Autism and Developmental Disorders*, 1-11. <http://dx.doi.org/10.1007/s10803-018-3696-5>

National Institute of Mental Health (2018). *Autism Spectrum Disorder*. Retrieved February 27, 2022, from <https://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd#>:

~:text=Autism%20is%20known%20as%20a,symptoms%20and%20ability%20to%20function.

Petrucelli, M., Ramella, L., Schaefer, A. J., Sheldrick, R. C., Carter, A. S., Eisenhower, A., ... & Mackie, T. I. (2021). A Taxonomy of Reported Harms in Pediatric Autism Spectrum Disorder Screening: Provider and Parent Perspectives. *Journal of Autism and Developmental Disorders*, 1-27.

Thompson-Hodgetts, S., Labonte, C., Mazumder, R., & Phelan, S. (2020). Helpful or harmful? A scoping review of perceptions and outcomes of autism diagnostic disclosure to others. *Research in Autism Spectrum Disorders*, 77, 101598.

United States Department of Education. (2020, November 24). *About IDEA*. Individuals with Disabilities Education Act. Retrieved October 24, 2021, from <https://sites.ed.gov/idea/about-idea/#IDEA-Purpose>.

Vanderbilt's Iris Center (n.d.) Information Brief Least Restrictive Environment (LRE)

<https://iris.peabody.vanderbilt.edu/wp->

content/uploads/pdf_info_briefs/IRIS_Least_Restrictive_Environment_InfoBrief_092519

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