



Bryant University

HONORS THESIS

Examining the Disproportionate Diagnosis of Learning Disabilities

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ABSTRACT

This thesis examines various factors and intricacies of inequitable diagnoses of learning disabilities, specifically looking at the differences that women and BIPOC students have in their diagnosis journey. Grounded in exploring access services and disability rights/justice both at Bryant University and elsewhere, this thesis investigates the intricacies of social class, societal norms, and cultural effects on learning disability. It compares what the secondary data reports on diagnosis of learning disabilities to the experience of Bryant students. Additionally, it examines gaps found in secondary research.

INTRODUCTION

There are many layers and intricacies to why women and people of color do not get diagnosed with a learning disability as often as white men. Some include gender, socio-economic status, and cultural factors. Gender affects diagnosis because different genders present differently when they have learning disabilities. Socio-economic status affects diagnosis because often the testing for a disability is very expensive (Ben-Moshe, Liat et. al. 2014). Also, the school system a child goes to is often the first point of contact for determining whether a child is struggling due to a disability. If the school system does not provide proper training and resources to determine if a child has a disability, they slip through the cracks (Shifrer, D., Muller C. et al, 2011). Often school systems of lower socioeconomic classes do not have a lot of funding and therefore do not report children for testing even if a learning disability is suspected (Shifrer, D., Muller C. et al, 2011).

Cultural norms also have a large effect on getting diagnosed with a disability. This is because the tests that are often administered in schools were made for white students and are not as accurate for other cultures (Shifrer, D., Muller C. et al, 2011). This is because every culture has behavioral differences that affect development so a test made for one culture may not be suited for all cultures.

Finally, society has a large stigma on disabled peoples. For example, people often see a disability as a bad thing and disabled people are often seen as lesser. The large negative stigma causes parents of children to try to avoid a diagnosis to avoid their child being labeled and additionally adults avoid labeling themselves (Lisle, 2014).

LITERATURE REVIEW

Introduction

As of 2021, around 15% of school children are diagnosed with a learning disability in the United States (American Psychiatric Association). Learning disabilities, also known as a specific learning disorder, are classified as “neurodevelopmental disorders that are typically diagnosed in early school-aged children, although may not be recognized until adulthood. They are

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characterized by a persistent impairment in at least one of three major areas: reading, written expression, and/or math,” (American Psychiatric Association). However, the statistic of 15% is most likely a lot lower than how many school children actually have disabilities. It is reported that around 30-50% of adults in the population have an undiagnosed learning disability (Lisle 2014). Meaning this 15% should be much higher.

Furthermore, there is evidence that women are diagnosed with learning disabilities far less than men, as it is reported that men are 1.7 to 2.7 times more likely to be diagnosed with a learning disability than women (Shifrer, 2011). Research suggests that BIPOC students also have a very complex relationship with diagnosis, in some cases getting diagnosed too often and other cases not getting diagnosed enough and are struggling because of it (Shifrer, 2011).

Due to these discrepancies in diagnosis this paper will examine the root causes of the inequitable diagnoses of learning disabilities. Based on literature there are many layers to the inequitable diagnosis of learning disabilities. The four main layers that will be addressed in this paper are the general societal stigma on disability, socio-economic status, and cultural factors.

Stigma on Learning Disabilities

There is a clear negative stigma on people with learning disabilities. In a study conducted by Kelsey Lisle and Joel Wade it found that participants viewed people with learning disabilities to be less favorable in terms of personality and success. They also viewed them as less physically attractive due to the “spread effect” which is when someone with a deficit in one area is suddenly assumed to have a deficit in multiple areas. Men with disabilities were viewed as weaker and more feminine, and women were viewed as extremely weak and unintelligent (Lisle, Wade 2014).

It has also been reported that teachers and professors view students with a learning disability as less intelligent, lazy and harder to teach (Lisle, Wade 2014). These negative attributes that come with people’s perception of learning disabilities create a large struggle for the students experiencing disabilities. So much so that by the time students with learning disabilities reach college only 6% report it to the university (Lisle, Wade 2014). This is a major reason parents may hold off on a diagnosis. They do not want their children to be labeled in this way.

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Additionally, students who are older may not get evaluated when they are older due to the fear of being viewed this way as well.

Socio-Economic Status

Socio-economic status plays a key role in a child's life. Poverty has been shown to affect development and can lead to learning disabilities or just general academic struggle (Shifrer, 2011). Also, people who are in lower socio-economic groups do not have great access to health care (Ben-Moshe, Liat et. al. 2014). This may affect disability diagnosis because it may be harder for them to have their child evaluated due to high cost. They also don't have access to preventive screenings as much as higher socioeconomic groups do leading to less early detection (Ben-Moshe, Liat et. al. 2014).

Being in a lower socio-economic class also causes a child to be in a lesser funded school, which makes it harder for the teachers at that school to identify learning disabilities. This is because the schools with lower funding do not do as much training on disability screening and also don't generally have the money from the state to do the testing a child might need to determine if they have a learning disability (Phillips, Odegard, 2017). Additionally, these schools that have lower funding also tend to have students with lower reading levels, making it harder to distinguish if a child has a learning disability related to reading or that they are struggling just because the literacy rates are lower (Phillips, Odegard, 2017).

Gender

As mentioned above, research shows that men are more likely to get diagnosed with learning disabilities than women. Men develop slower both cognitively and physically both in the womb and adolescence. This can cause a higher probability for birth defects which can cause learning disabilities. This is because the extra time that male brains are underdeveloped allows for more time with sensitive periods while in the womb where the brain and overall development can be affected (Nass, 1993).

Additionally, the fact that men develop slower means that they are a bit behind the females in the classroom as well. This means women perform at a higher level in the classroom at a baseline.

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This can cause a problem because teachers are often the first touch point for diagnosing a learning disability and they do this by looking at who is struggling. Oftentimes, since the men in the class are struggling more than women due to being cognitively behind, women do not appear to be struggling as much as they are (Shifrer, 2011). This causes women with disabilities who are doing better academically than the men to not get detected (Shifrer, 2011).

Another reason women do not get diagnosed as much as men is that the two sexes behave differently when faced with a disability. Men often have behavioral issues that the teacher will be able to catch and identify as a potential learning disability (Nass, 1993). Whereas women are able to mask their struggles better and just work harder to compensate (Nass, 1993). Also, the “symptoms” used to detect learning disabilities are the symptoms that often show up in males and not females due to the overrepresentation of males (Shifrer, 2011). This means that since women do not exhibit the same symptoms as men when having a learning disability, they may be missed because the symptoms were developed in a mostly male population. In other words standards for diagnosing disabilities are based on male subjects (Shifrer, 2011).

Cultural Norms and Representations

Cultural norms and representations factor into the inequitable diagnosis of students because every culture is different, therefore each culture is going to have different symptoms for learning disabilities, which affects students in two ways. The first being that the tests and screening tools used by teachers and psychologists to determine whether a child has a disability were made based on how disability presents in white people (Shifrer, 2011). The tests being created based on the diagnosis of white people is problematic because the signs for a white person having a disability are different from that of another culture (Shifrer, 2011).

The second way it affects students are that students of BIPOC cultures get over diagnosed with learning disabilities due to deep seeded racism and bilingualism (Shifrer, 2011). There is evidence in this based on that Native Americans are 1.8 times more likely to be labeled with a disability (Shifrer, 2011). This statistic is not due to the fact that Native Americans actually have disabilities. More often it has to do with the fact that there has been a long history of separating Native Americans and African Americans into special education (Ben-Moshe, Liat et. al. 2014).

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Additionally, bilingual students or students that are English learners are over diagnosed as well. They are 1.1 times more likely to be labeled with a learning disability (Shifrer, 2011). This is due to the fact that they may be struggling with language for other reasons than having a disability, but they still get put into special education (Shifrer, 2011). The overdiagnosis of BIPOC students is problematic because although they may be struggling, they will not get the type of support they need from special education if they do not have a learning disability. There is a gap in the research on how different cultural beliefs affect parents getting their children tested. As some cultures may be less apt to acknowledge weakness.

Conclusion

Female students are underdiagnosed with learning disabilities due to the fact that the standards for diagnosing disabilities are based on males. Students in lower socioeconomic groups are not being diagnosed because they do not have enough resources. Additionally, BIPOC students are over diagnosed with disabilities due to racism, language, and academic difficulties, as BIPOC students may not have a learning disability but the difficulties they have cause them to perform at a lower-than-average skill level landing them in special education. There are gaps in the research in how the parent is involved in the process of getting their child diagnosed and how the parent's culture affects their decision on getting the child diagnosed. This thesis evaluated these problems further while also diving deeper into the factors discussed above.

RESEARCH QUESTION

This thesis had four primary research questions: (1) Why don't people with learning disabilities get diagnosed? More specifically, why are women disproportionately diagnosed more than men? And why are BIPOC over-diagnosed in some situations and underdiagnosed in others? (2) How does class and family income inform the lack of learning disability diagnoses? (3) How do cultural and societal norms affect the diagnoses of learning disabilities? And (4) Does the secondary research evaluated here hold up against the experiences of the Bryant Community?

RESEARCH METHODOLOGY

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This thesis was conducted in two parts. The first part was examining secondary research that informed the topic of learning disabilities and diagnosis. The second part was conducting primary research through a survey and follow up quantitative interviews. The survey collected preliminary data on student's diagnosis story and basic socio-graphic and demographic information. The interviews helped to gain a bigger picture understanding of what the student's experience with diagnosis and overall disability was like.

The survey was sent out to all students registered with access services that have a learning disability. Then from that survey specific students were picked based on their responses. In the beginning only students who got diagnosed from ages 16-21+ were selected to be interviewed as it was thought that these individuals would better remember their diagnosis process. However, due to not receiving enough participants from reaching out to this group the target group was expanded to include students diagnosed at ages 11-15.

Additionally, the group included anyone who reached out to be interviewed, as it was advertised that they could do this in the email that included the survey if they wanted their story to be told. This group was added because if they really wanted to tell their story the thought is that it must have valuable information. Additionally, self-identified BIPOC, bilingual, and women students were included as the research questions and project at-large were heavily geared towards this population.

SURVEY QUESTIONS

- Do you have a learning disability?
 - Yes/ No
- Did you receive accommodation for the current semester?
 - Yes/No/ I'm unsure
- How old were you when you were diagnosed?
 - 0-5
 - 6-10
 - 11-15
 - 16-20

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- 21+
- How were you diagnosed?
 - I got diagnosed through testing provided at my school
 - I got diagnosed through my school sending me to get tested
 - I got diagnosed by being tested privately
 - I'm not sure
- How did you pay to get diagnosed?
 - The state of school funded my testing
 - Private insurance funded my testing
 - I paid out of pocket for my testing
 - I'm not sure
- At what age did teachers or parents first express that they thought you might have a learning disability?
 - 0-5
 - 6-10
 - 11-15
 - 16-20
 - 21+
- Who recommended you get tested for a disability?
 - A teacher recommended I get tested
 - A doctor recommended I get tested
 - A parent recommended I get tested
 - Other
- Do you believe that your race, ethnicity or socioeconomic status impacted when or why you were diagnosed?
 - Yes
 - No
 - Maybe
- Are you bilingual?
 - Yes

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- No
- What is your first and second language? (Open response)
- Are you a first-generation college student?
 - Yes
 - No
- Please select your gender
 - Male
 - Female
 - Non-binary
 - Prefer not to say
- Please select your age
 - 18-24
 - 25-29
 - 30-50
 - 50+
- Please select which category below describes you best
 - African American
 - Asian
 - Latinx/Hispanic
 - Am Ind/AK ntv/Ntv HI/Pac Isl
 - White
 - Multi Racial
- If you are from the United States, what state did you receive the majority of your schooling? (Open response)
- Are you an international student?
 - Yes
 - No
- Would you be willing to be interviewed by Rebecca Reynolds about your experience with learning disability diagnosis?
 - Yes

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- No
- I need more information
- Please enter an email address and/or phone number where you can be reached if you would like to be interviewed (open response)

INTERVIEW QUESTIONS

- *Have you been diagnosed with a learning disability?*
- *If you feel comfortable sharing, what disability do you have?*
- *What led you to get a diagnosis?*
- *Do you speak any other languages?*
- *What state are you from?*
- *If you feel comfortable sharing, would you consider your town wealthy or not?*
- *Were you put in special education before you had a diagnosis/ What about after? / Did it help?*
- *When was it first suggested/ how was it suggested that you have a learning disability?*
- *When did you get formally diagnosed?*
- *How did you get diagnosed?*
- *Did you have any struggles with getting a diagnosis?*
- *Can you describe the barriers to diagnosis in more detail?*
- *Has your diagnosis helped you or hurt you in any way?*
- *Do you believe the diagnosis is accurate?*
- *Do you wish you would have gotten a diagnosis sooner? Do you think it would have helped?*
- *Do you have accommodations, or have you ever had accommodations that you have used throughout your educational career?*
- *Do you think having those accommodations sooner would have helped?*
- *Do you feel the stigma on learning disabilities has affected you in any way?*

ETHICAL CONSIDERATIONS

The first step to starting this thesis was getting it approved by the Internal Review Board (IRB) at Bryant to make sure the study did not have any ethical concerns or would harm any participants. This process was quick, and it helped to make sure it was considered how to handle the more sensitive topics in this research. For example, the survey that was sent out was also the way contact information was collected if the person agreed to be interviewed. Therefore, the questions in the survey had to be not too personal because they were connected to their names.

Another ethical consideration was making sure that students that were selected to be interviewed were not close friends with the interviewer. This is because the interviewer has a learning disability and is part of a club with many other students with learning disabilities. To make the research more authentic only students that were not close friends to Rebecca were chosen. One friend of hers was selected to do the first interview, a practice run.

Also, the interviewer was very close to the research as they have a disability as well. That was kept in mind to make sure they did not bias the research by adding information that was not objective or based on factual data to the interviews and thesis as a whole.

Additionally, as the topic of disabilities, race and sex are sensitive, the questions that were asked in both the survey and, in the interviews, had to be worded very neutrally. The interview questions are included in the appendix.

RESEARCH RESULTS

Survey Results

The survey went out to 170 students. Out of those students 44 responded. However, after cleaning the data and taking out anyone who did not have a learning disability or did not finish the survey the number went down to 35 students. The survey asked a variety of questions about the student's diagnosis journey and demographic information. The purpose of this survey was to get some data before I started interviewing and to get participants. The survey asked for people's contact information at the end of the survey if they felt comfortable being interviewed.

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Additionally, it helped me to better select my participants as I was able to target groups that would help answer my research questions.

Participant Information

The breakdown of the participants included 20 males and 15 females. 31 participants identified as white, 2 as Asian, 1 as Latinx/Hispanic and one as multiracial. Five students identified as bilingual, and 5 students were first generation college students.

Participant's Diagnosis Journey

Age

36.11% of participants were diagnosed with a learning disability between ages 6-10 years old. The next largest age group was 0-5 at 25% followed by 11-15 at 16.67%. The last two age groups 16-20 and 21+ both fell at 11.1%. Most students surveyed were diagnosed at a younger age. However, something interesting to note was that out of the 11.1% of students that were diagnosed later in life at 21+, 75% of them were females.

Additionally, another item the respondents were surveyed about addressed whether it was first noticed by a parent or teacher that the child was exhibiting symptoms of a learning disability. The majority of respondents, 47.22%, reported that they first had their symptoms noticed at ages 6-10, the same age bracket that students were diagnosed. Zero-5 was the next largest age group, at 33.33% which was also the second largest age bracket for the age when people were getting diagnosed. The last three age brackets were 16-20 at 8.33%, the 21+ and 11-15 at 5.56%.

The interesting thing to note is that the percentages for students that were diagnosed vs. when it was first expressed that a student might have a learning disability is lower for the first two groups which is where the majority of the participants fell. For example, 42.77% first noticed at age 6-10 however, only 36.11% were diagnosed. Same with ages 0-5, 33.33% had symptoms noticed but only 25% diagnosed.

Testing

Many students were tested privately outside of the school as 67.67% of respondents chose that option when asked how they got tested for a learning disability. The next most common response was that they were tested in the school, or the school sent them to be tested at another location.

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27.78% of respondents answered this way. Finally, the last 5.56% were unsure. This means that for most participants their families had to figure out how to get them tested on their own. As will be seen later through the qualitative results, this was a big hurdle in students being diagnosed and getting the help they needed.

Additionally, the results varied for how families of students paid for testing. Out of the respondents from the survey only 13.99% of students' families got funding from their state or school to get tested. 36.11% did have help from private insurance, but 20% had to pay the cost of the test out of pocket. The remaining 30.56% of respondents were unsure of how they paid for the testing. This means that out of the sample collected families either had to use private insurance or pay for the test out of pocket. Which can be a hurdle for some who do not have insurance or the funds to pay for the testing as it can be overly expensive.

In the survey participants were asked who recommended they get tested for a disability. Based on the results teachers and parents were the ones who recommended that the students get tested for a learning disability. 36.11% of respondents reported that it was a teacher that recommended that they get tested and 33.33% reported that it was a parent. 8.33% of respondents selected a doctor recommended they get tested. 22.22% of respondents selected "other" for this category. This may be because the survey did not have an option to select that it was themselves that identified that they needed to get tested or that another family member could have suggested that they need to get tested. Overall, this data suggests that teachers and doctors were the first point of contact for the students that were surveyed.

Interview Results

The purpose of interviewing some of the students that responded to the survey was to get more detailed stories of Bryant students' experience with their diagnosis journey to answer the fourth research question of this thesis: Does the secondary research evaluated here hold up against the experiences of the Bryant Community? The research was evaluated based on the three other research questions: (1) Why don't people with learning disabilities get diagnosed? More specifically, why are women disproportionately diagnosed more than men? And why are BIPOC over-diagnosed in some situations and underdiagnosed in others? (2) How does class and family

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income inform the lack of learning disability diagnoses? (3) How do cultural and societal norms affect the diagnoses of learning disabilities? The population interviewed made it difficult to fully answer the questions.

Nine individuals were interviewed. Out of these individuals, six of them self-identified as male students and three identified as female. None of the participants interviewed self-identified as BIPOC individuals. Therefore, the second part of the first research question was not answered by my interviews, only the secondary data. However, each participant had a unique story that provided insight into the disproportionate diagnosis of learning disabilities. Many insights were learned from the interviews that did not fall under the previously defined research questions. When the participants are named in the following sections all names have been changed to preserve identities.

Disproportionate Diagnosis of Women

This section addresses the second part of the first research question of why women are disproportionately diagnosed compared to men. The sample size for Bryant students that self-identifies as women was much smaller than anticipated as only three women were interviewed. That being said, the data found from these three interviews was very powerful. The three stories that are in this section are from Emily, Bethany and Sarah.

Based on the secondary data reviewed it was found that there are a few key reasons that women do not get diagnosed with learning disabilities. One major factor found in the secondary data is that men and women develop cognitively at different speeds causing the symptoms of learning disabilities of women to not be caught (Shifrer, 2011). Meaning that men take a bit more time to develop meaning the women in the classroom are often ahead of the boys to begin with so if they are struggling it might not be seen because they are still doing better than the boys (Shiffer, 2011).

Bethany, Sarah and Emily's story align with this fact pulled from the secondary data. As all three of them were diagnosed later in life. Meaning that they did not get diagnosed when they were younger because they were not noticeably struggling in their classes. Bethany was diagnosed the

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earliest as a senior in high school. She is now a freshman at Bryant. Sarah was diagnosed when she was a junior in college and is now a senior at Bryant and Emily was diagnosed the summer of her junior year of college and is also now a senior at Bryant. All three girls mentioned struggling with the symptoms of their learning disabilities their entire lives but only get a diagnosis as young adults.

Another reason the secondary data points out that women do not get diagnosed is that women overcompensate for their disability and work harder so that they still perform, whereas men are more likely to have noticeable symptoms (Nass, 1993). This can also be seen in all the girls' stories.

They were not diagnosed because their symptoms were not noticed because they were doing well enough in school even though they had to work extremely hard to perform. For example, Sarah talked about this experience. She explained that her school did not want to test her because she was doing so well academically. "They were saying that I was too smart. Because I was in AP classes and I was excelling, like I had really good grades and GPA. So, they were like, Yeah, you're fine, (Sarah)." However, she later went on to say that even though she had good grades she did not feel great mentally. "I was dying like I would work so much harder than everyone else, (Sarah)."

The only way both Sarah and Bethany got a diagnosis is that they started struggling so much that the people in their lives finally believed them that they had something that they might need help with. This was in particular a big struggle for Bethany as no one believed her that she had a disability for the longest time. She described how this experience feels in her interview. "And no one believes you, so you don't know what to do. You feel invalidated because you don't know what's wrong and that you can't do certain things." She goes on to talk about how she did well in school when she was younger but when she started struggling when she was older it was not a great experience. Saying that it is a hard experience "When you did super well when you were younger and all of a sudden like you don't know if you're stupid because the material's too hard or you can't you don't deserve to be in the classes that you're in, (Bethany)."

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Disproportionate Diagnosis of BIPOC Individuals

None of the participants interviewed were self-identified as BIPOC individuals. Therefore, it could not be validated if the secondary research aligns with the stories of students from Bryant university. However, to answer the second part of the first research question: why BIPOC individuals are both over-diagnosed and underdiagnosed, secondary data will be provided. There are a few reasons why BIPOC individuals are sometimes over-diagnosed for learning disabilities. The biggest reason has to do with the bias individuals have over these groups. For example, racism has a substantial impact on diagnosis. As mentioned earlier Native Americans are 1.8 times more likely to be labeled with a learning disability (Shifrer, 2011). Additionally, there is bias with bilingual students, as bilingual students are 1.1 times more likely to be labeled with a learning disability (Shifrer, 2011). Therefore, how BIPOC individuals are viewed has an impact on potentially getting over diagnosed because they are labeled as disabled when they are not.

However, BIPOC individuals are also underdiagnosed. This is largely due to the socio-economic demographic BIPOC individuals tend to fall into lower socioeconomic classes. Research shows that people in lower socio-economic groups have less access to resources that help them to potentially get diagnosed with a learning disability (Ben-Moshe, Liat et. Al. 2014). One resource in question is access to healthcare and preventative screenings due to high costs (Ben-Moshe, Liat et. Al. 2014). Also, the school system a child is put into is another resource controlled by socio-economic groups. This is because schools that have lower funding do not provide good screening for students with learning disabilities (Phillips, Odegard, 2017).

Impact of Class and Family Income on Diagnosis

Through secondary research it was found that money is a big barrier to diagnosis and getting the support to get to a diagnosis. This is because socio economic class really affects opportunities of diagnosis due to not having access to resources. The two biggest resources that people in a lower social class do not have access to are health care and education. Access to healthcare is important in the diagnosis process because it provides screenings that may help to detect if a child has a learning disability (Ben-Moshe, Liat et. Al. 2014). Additionally, education is important because students in lower socio-economic groups go to school with less funding. Schools with less funding have less resources for training for teachers in detecting a disability and resources to test

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students. They also have less funding for special education so teachers may be hesitant to label students in this way (Philips, Odegard, 2017).

Although socio economic class was found to be a major barrier in the secondary data, none of the students who were interviewed described themselves as falling into this category. Therefore, the secondary data could not be validated by the interviews in this section as well.

However, a gap in the secondary data was discovered when talking about financial situations with the students interviewed. The interviews exposed that there is often a financial burden in getting help after getting a diagnosis. For example, two of the male individuals, Noah and Daniel, discussed financial burdens to getting the help they needed in their interviews.

Noah started struggling in school significantly when he was in 5th grade. He got tested close to when he started struggling between his 5th-7th grade years. He did not have any financial barriers with paying for the testing. However, once he had the results, he knew he needed to leave the public school system and look into something else that could better support his learning disability. He is from MA and in this state, they offer to pay for a private school if it can be proven that the public school system will not provide the support needed for a student with a learning disability. However, the state claimed that he did not have a severe enough disability to qualify for this. He said that it was a big financial burden for them as the cost of school was worse than paying for a college education. In his interview he talked about how essential the private school he went to was: “I wish that everyone with a learning disability had access to that kind of education. Because it changed my life. I wouldn't have gone to college [without it].”

Daniel, another male student interviewed, had a similar story but did not have the funds to pay for a private institution, so he went the route of trying to get the funds from the state as he is from MA as well. Therefore, his family got into legal battles to help pay for his education. He talked about how this was hard on his family and that even when the state did agree to pay, they would delay as much as they could. “We never got paid by the school district for anything until my senior year. We footed the bill for a very long time. And then they would pay like every once a while just to keep the attorneys happy. They'd give some money to pay for something and then and then the majority of the cost was on us until senior year, and then they finally did some retroactive payments.”

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Both male students kept emphasizing how important the private education was to their successes and ending up at Bryant. However, they both talked about how hard it was to pay for it and that this was a burden that both families had to take on. This raises questions on how education is treated for people with disabilities and shows that if students do not have the financial resources, they will be much less likely to make it through to higher education.

Cultural and Societal Norms

Cultural Impact

The third research question asked in this thesis was how cultural and societal norms affect the diagnosis process. It was evident through the secondary research performed that cultural and societal norms affected the diagnosis process in a significant way. However, all the participants from the interviews identified as white individuals. Therefore, the data on cultural norms could not be validated by the interviews. The secondary data showed that the recognized symptoms for learning disabilities come from evaluating white people (Shifrer, 2011). However, every culture acts in different ways due to different cultural norms (Shifrer, 2011). Meaning that this may be a reason that some do not get diagnosed because they do not present with the typical symptoms of a specific learning disability.

Societal Impact

Additionally, the second part of the third research question evaluated whether societal norms have an impact on the diagnosis of learning disabilities. Secondary research shows that societal norms contribute a large amount to the disproportionate diagnosis of learning disabilities. This is because there is a clear negative stigma on people who have learning disabilities which causes students themselves or parents to not want to be labeled and take on that stigma. The perception of a person with a learning disability is extremely negative. Studies have shown that people labeled with learning disabilities are thought to have less favorable personalities and be less successful (Lisle, Wade 2014). Additionally, in an educational sense teachers often automatically perceive students with learning disabilities as less intelligent, lazy and harder to teach (Lisle, Wade 2014). This negative stigma is so strong that by the time students with learning disabilities reach college only 6% of them decide to report it to their university (Lisle, Wade 2014).

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This was certainly evident with the interviews conducted. As the stigma had touched each of the interviewee's lives in different ways and in varying degrees. For example, Brian met it when he was in middle school and other students would not understand why he was not in art class.

“When I got to middle school. I was like, hey, why am I doing this again? Because during my learning center time, there was art class. So, I would go to a learning center instead of art. So, people would say: hey, why aren't you going to art? And I was kind of like, I don't know.

(Brian).” He went on to talk about how that didn't feel the best and that he wasn't the most comfortable talking about his disability back then but now he is more open even though he is fully aware of the negative stigma.

Timothy had a different experience where the negative stigma on learning disabilities really affected his classroom experience where he felt he was often quickly thought to be one causing trouble just because his teachers knew his diagnosis. “I think it was pretty demeaning of them to, you know...automatically they would side with an opposite party of a situation if a situation ever occurred because they knew that I had a disability. They're like, oh, it's just the kid with the disability, causing trouble again, (Timothy).” He went on to describe a few stories that he still remembers vividly where he was automatically assumed to be the one in the wrong when maybe he did do something slightly wrong but was punished way more than he should have been and to a higher degree than the other children involved.

Finally, Bethany discussed how the stigma on learning disabilities often causes people to not really understand what it is like for someone who is struggling with a disability. She talked about how only the “fun” or “relatable” parts are glamorized. “When people are like, oh, I am being so ADHD or stuff right now. I'm like, well, it's not just like...you're so energetic, like you're running out like, stuff like that... Like it's not just you [are] bouncing off the walls. I've stared at my computer at the cursor for like eight hours and like, nothing gets done and that's more like that. Stuff like [that] no one really like wants. That's not like the glamorized part of it. So, no one talks about that stuff (Bethany).” There are many layers to the stigma on learning disabilities and it is clear that the public perception on learning disabilities has a big impact on diagnosis.

LIMITATIONS

Time Constraints

There were a few obstacles when completing this project. The biggest challenge was the time constraint of this thesis. This is because this thesis was started a bit later than usual as typically, they are started in the spring of the student's junior year, however this thesis started November of the student's senior year. Therefore, the qualitative portion of this project (the interviews) was squeezed into one month from February to March, where usually qualitative research takes six to eight months.

The quantitative portion took a long time to develop, due to having trouble deciding the best use of the survey. There were two options. One was to just use the survey to get potential participants for interviews and the second was to gather some data about the overall population then ask people if they felt comfortable being interviewed. It was a tough decision because the second option provided more data that might be useful, but also connected personal identifying information to people's names and it was thought that this might deter people from saying they want to be interviewed and was also an ethical consideration. After consultation with the IRB at Bryant it was decided that it was all right to go with the second option. However, this consideration process of deciding what option to go with and creating the survey took about a month and really slowed down the process as this had to be completed before the interviews could start.

Survey Missights

Another limitation to this project was some of the survey questions were worded in ways that were unclear to the participants. This caused a couple questions on the survey to not be answered in the way they were intended to be answered. For example, there was a question that asked, "who first suggested that you should get tested for a learning disability?" The options that were provided for the students to select were "teacher, doctor, parent and other". Through the interviews it was found that those options left out a few very specific people such as the person themselves identifying that they have a disability or other family members often identified that an individual may need to get tested. Therefore, it would have been good to add that to the options, so fewer people picked the other option.

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Also, the last question that asked participants to leave their contact information did not function the way it was intended. This question was intentionally left as an open response format so that participants felt like they wanted to share more about their stories than they could by leaving the best way to contact them. It was intended that participants would write in their actual email address or phone number as no personal contact information had been taken in the survey before this question. However, many participants seemed to think their contact info had already been collected as they just left the word “email” or “phone” instead of giving me their actual contact information. This proved to be difficult when trying to interview people as I could not reach out to all participants who consented to be interviewed.

Interview Scheduling Difficulties

An unforeseen difficulty that doing research with this population was that scheduling was a bit difficult. This is because time management is a big struggle for this population and there were many interviews where people were late which made the interviewer late to the next interview. Additionally, there were a few no-shows where the interviews had to be rescheduled. This made it difficult to get in the number of interviews that the investigator wanted as some people who no showed were not able to reschedule.

CONCLUSIONS AND FURTHER DISCUSSIONS

With this type of qualitative research comes unexpected results. There were many themes that popped up through the interviews that were not included in the themes provided by the research questions or the secondary data. Two themes seemed to be the most significant based on the participant's stories. The first theme is that there is no standardized process to be diagnosed with a learning disability and that opportunities really dictate how your diagnosis journey goes. The second theme is that categorization into special education is complicated and may not be the solution to helping students with learning disabilities. Every student touched on these themes in their interviews showing that further research should be done in these areas.

Need for Standardized Process

This theme arose because every participant had a different story on how they were diagnosed with a learning disability. It all boiled down to what opportunities they had available to them and who was in their life. Some identified that they themselves had a learning disability such as

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Bethany did, whereas others had a family member or teacher suggest that they get tested due to seeing them struggle. There was no one way that a person found out they had a learning disability.

Additionally, once it was identified by either themselves or another individual that they may want to get tested there was no clear path to getting answers. Some went to their doctors to get answers, only to get referred to a psychologist for further testing. Others tried going to the school for help. Others tried to do the research on their own. However, almost every individual interviewed discussed the fact that the path was not clear on how to get a diagnosis being a huge barrier to getting diagnosed.

For example, Daniel talked about the struggle of not knowing what to do when his family was faced with the fact that he most likely had a learning disability. He said: “The school says I'm not trying at all. And that's not the case. The story didn't add up. My mom was like, okay, we'll, go find someone to get me tested. I don't even know what we were doing. We had no clue what we were doing back then. It was the first time anyone in our family had ever dealt with learning disability, (Daniel).” He went on to talk about how he ended up having to get tested by a few different psychologists as he did not know what tests he needed done the first time and when he went back to the public school system to get accommodations, they kept telling him he needed more testing to fully determine his accommodations. He said it was a big struggle for his family and that not knowing what to do made the process much harder.

Additionally, Bethany echoed this in her story talking about how she had to figure the diagnosis process out on her own. It took her a couple years to figure it all because she kept hitting roadblocks and getting re-directed trying to figure out the best path to a diagnosis and getting accommodations. She expressed how exhausting the whole process was and that it made it very difficult to keep trying to get answers.

Therefore, in the researcher's opinion there should be further research done on the diagnosis process of learning disabilities. Currently there is not a clear path or answer and the fact that families must do their own research and advocate for their children is a big barrier to diagnosis. If a child does not have a support system like Bethany, didn't it can be a long hard journey to figure it out all on their own and even with a support system it is still hard.

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The Implications of Special Education

An interesting theme that often was discussed when talking about the diagnosis journey was special education. Each student interviewed had a unique story about how they were involved in special education as each school and school system handles special education differently. Some were put into special education before they even got an official diagnosis. The students interviewed did end up getting an official diagnosis. However, it is possible that a student gets put into special education without a diagnosis and ends up never receiving one and struggling later down the line.

When discussing their diagnosis journey and being in school all the participants mentioned similar themes when discussing special education. The students discussed that it was not always the most helpful thing to be put into. This is because it caused unforeseen problems such as being made fun of by peers for being taken out of classes. This is because it was obvious to their peers that students were special education by the fact that they were taken out of certain classes. This caused their learning disability to be more obvious to their peers causing them to be vulnerable which caused mental health implications for some.

Additionally, the students interviewed discussed how they didn't always get the help they needed due to so many students with different needs being in the same room. This is because there are a wide range of reasons that a student is put into special education and some reasons require more attention from teachers than others.

Timothy talked about this in his interview. He described how special education did not really help him when he was growing up. He said how he felt that instead of trying to understand how he learns they just tried to force him to learn a specific way. "They don't really seem to want to put in the work or effort. They just want to kind of mold [you] into what they want, (Timothy)."

However, even though it wasn't always a positive experience it did help some. For example, Brian talked about how he used his special education time as a study hall and when he was able to get attention it did help. He did say at times it was hard to get attention though due to the

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different needs in the room. However, due to the amount of people in his special education program his school tried to remove him from these services because he was doing well in school. In his interview he discussed how his parents had to fight to get him to keep his IEP so that he could have it for college. “They said they had to fight for me to get an IEP. Especially like in high school. I guess they really fought for me and I keep it because they wanted me to have for college (Brian).”

Special education obviously serves a purpose but looking at the implications presented above it raises the question of whether it is really functioning in the way it is supposed to. It is much better than having no support for students with disabilities, however, is it serving the function it is created for? Through these interviews the researcher believes that there could be a better way to help students with learning disabilities as often special ed does not seem to help as much as it hurts. Further research should be done in this area.

Both above-mentioned themes require further research. However, as a topic the topic disproportionate diagnosis of learning disabilities should be continued to be explored as it is a real issue that affects the lives of many. A diagnosis helps end the struggle of a student who believes that they are stupid and not as good as their peers. A diagnosis helps level the playing field.

PERSONAL STATEMENT AND OBSERVATIONS

I decided to further examine the diagnosis journey of others with learning disabilities due to my personal experience with learning disability. I was diagnosed with dyslexia last year, after struggling for years. It was suggested that I was tested when I was a child, but when I went to the psychologist for a formal evaluation I was sent away. After talking to me for a few minutes the psychologist told my parents that I was smart, would make it through and did not need a label applied to me, that my disability wasn't that bad.

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However, it was bad. There were years of late nights doing homework taking twice as long as my peers. Not to mention I had very low-self-confidence when it came to school due to how much extra time and effort I took.

When I finally got the diagnosis, later in life after having a particularly hard time in college, it truly helped me to realize I was not stupid and to gain the confidence I needed to really be myself. I joined an Honors Society on Bryant's Campus called Delta Alpha Pi (DAP) for students with disabilities. Here I heard many stories that aligned with my own. Every student in DAP had struggled on their path to diagnosis and what came after diagnosis. However, there were mostly white men in the society. Out of the entire group there are only three females who are a part of DAP. This bothered me so I started doing research and found that women often get diagnosed much less often than men. I was one of those women for a while. I found out many more details of disproportionate diagnosis which troubled me.

However, the biggest thing I learned is that no matter who you are, having a disability is hard due to so many factors and that needs to change. That is why I am motivated to educate people on learning disabilities and the disproportionate diagnosis of them. As I believe that if people become more familiar with these issues fewer people will struggle with getting a diagnosis because the path to diagnosis is different – and can/ought to be more accessible – for everyone.

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