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THE LIVED EXPERIENCE OF ADOLESCENTS WITH DYSLEXIA

BY

JOSEFINE M. GARCIA
Bachelor of Science, University of New Hampshire, 2007

THESIS

Submitted to the University of New Hampshire
in Partial Fulfillment of
the Requirements for the Degree of

Master of Science
in
Communication Sciences and Disorders

September 2009

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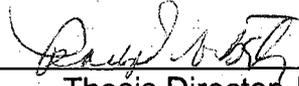
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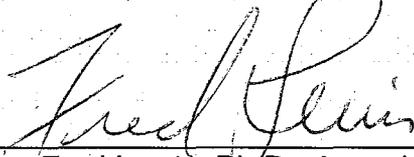
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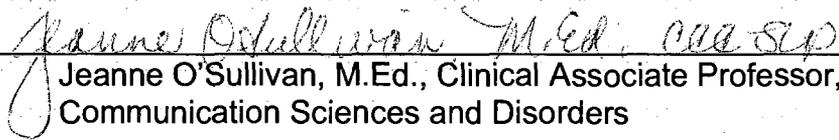
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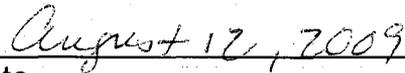
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DEDICATION

For Eric-- I could not have completed this project without your unyielding support.

Y para mi familia, gracias por siempre creer en mi.

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ABSTRACT

THE LIVED EXPERIENCE OF ADOLESCENTS WITH DYSLEXIA

by

Josefine Garcia

University of New Hampshire, September, 2009

In this study, interviews with 8 adolescents between the ages of 13 and 16 were performed to explore how young people with dyslexia experienced school in terms of well-being, educational performance and challenges, self-esteem, peer relations, the roles of teachers and parents, and views on support. The elementary years of school seemed to be the most difficult for interviewees. While peer interactions were often seen as a crucial part of school, all students reported that they had experienced or feared ridicule from peers. Academic and personal self-esteem seemed low for all participants, and while many students saw their problems as limited to reading and writing, their responses showed that dyslexia transcends decoding and encoding and goes on to affect students in a variety of areas, including socially and emotionally.

CHAPTER 1

LITERATURE REVIEW

Dyslexia and Adolescence

Adolescence is characterized by a rapid shift in social, emotional, and educational needs (Long, MacBlain, & MacBlain, 2007). During these years, young people begin a self-examination process that helps them establish belief systems that will lead them into adulthood (Long et al., 2007). Research supports that individuals with learning disabilities (LD), including dyslexia, experience more "social, emotional, and motivational difficulties than those without LD" (Klassen & Lynch, 2007, p.494). According to Klassen & Lynch (2007), adolescents with learning disabilities undergo the same transitions as their peers, but with the added challenge of having significant deficits in specific areas.

By adolescence, many students with dyslexia have become accustomed to failure and have begun to suffer the effects of low self-esteem in their academic and personal lives. School is often a struggle from the start for children with dyslexia, and adolescence brings about additional challenges with the introduction of heightened social pressure, more complex reading and writing tasks, and foreign language courses. Although researchers have investigated self-concept and self-esteem among individuals with learning disabilities

(Klassen & Lynch, 2007), less individual attention has been given to dyslexia. Although researchers have analyzed many aspects of dyslexia, few have focused on the emotional repercussions of living with dyslexia in adolescence as students face increased academic demands and heightened social pressures. It is still relatively unknown how individuals with dyslexia in the United States cope during adolescence and how these students experience an education system that may be failing to meet their needs.

Background

Dr. Pringle-Morgan was the first to describe developmental dyslexia in 1896, when he wrote about an "intelligent teenager who had failed to read"(cited in Snowling & Stackhouse, 1996, p.1). More recently, Karande et al. (2007) have described dyslexia as the most common and best-defined specific learning disability (SpLD) and estimated that the prevalence of dyslexia in school children in the United States ranges from 5-11%. Rooted in the Greek language, the term dyslexia literally means *difficulty with (dys) words (lexis)* (Pollock & Waller, 1997). Although dyslexia is often linked to reading and spelling difficulties, the disorder can also interfere with an individual's ability to write, pronounce, and associate words properly (McClure, 2007). The National Institute of Child Health and Human Development (NHCHD), states that dyslexia "is characterized by difficulties with accurate and/or fluent word recognition and by poor spelling and decoding abilities" (McClure, 2007, p.86). It has also been proposed that dyslexia influences a student's speed and accuracy in ways that

affect reading, dictation, note-taking, spelling, mathematics, writing, organizational skills, and the completion of tests and exams (Riddick, 1995).

Many theories have attempted to explain dyslexia's underlying cause, including the view that the disorder is the result of visual deficits (Turner & Rack, 2004). Today, much research supports that the processing difficulties typically associated with dyslexia result from a phonological component of language, or the ability to notice, think about, or manipulate the individual sounds in a word ((McClure, 2007; Shaywitz et al., 1999). Researchers have found that phonological representation determines the ease with which a child learns to read, and it has been suggested that difficulty with phonologic awareness is the most salient characteristic of reading disability (Snowling & Stackhouse, 1996; Shaywitz et al., 1999).

Dyslexia and other learning disabilities share several defining traits, including an underlying neurological basis. These neurological deficits manifest themselves in the inefficient execution of mental operations related to learning, such as perception, memory, attention, and fine motor coordination (Sanders, 2001). Due to a shared genetic etiology, it has been reported that roughly 20% of children with dyslexia also suffer from attention-deficit hyperactivity disorder (ADHD)(Karande et al., 2007). For many years, it has been posited that reading deficits and language disorders tend to run in families. Behavior geneticists have now concluded that a boy whose father is dyslexic has a 50% probability of also becoming dyslexic and a 40% probability if his mother is the affected one

(Snowling and Stackhouse, 1996). Evidence also supports that girls have a slightly lower chance of inheriting dyslexia (Snowling and Stackhouse, 1996).

Individuals with dyslexia and LD tend to exhibit an uneven profile of cognitive abilities. Sanders (2001) described cognitive abilities as the discrete skills that make up general intelligence, including areas such as attention, perception, and memory (p.34). While the typical learner's profile may fluctuate mildly, those of individuals with learning disabilities can reveal significant peaks and valleys (Sanders, 2001). Students may be able to develop successful strategies that help compensate for their difficulties, but for many individuals, dyslexia and LD lead to academic struggles, social complications, and self-esteem problems that may last a lifetime. Although dyslexia has been documented for more than a century, there are many gains to be made in the understanding of its effects on individual development in adolescence.

Review of the Literature

Numerous studies have explored the characteristics of children with dyslexia including studies that have analyzed behavior problems, motor performance, and the profiles of children with dyslexia co-occurring with attention deficit disorder, but there is a scarcity of research that evaluates the effects of dyslexia on socioemotional development (Heiervang, Stevenson, Lund, & Hugdahl, 2001; Haslum & Miles, 2007; Karande et al., 2007). One related study investigated the relationship between having dyslexia and bullying (Singer, 2005). In this study, Singer analyzed the strategies adopted by Dutch children

with dyslexia to maintain their self-esteem when teased at school. The study sample was comprised of 60 Dutch children with dyslexia between the ages of 9 and 12 who attended mainstream schools. The children's coping strategies and perceptions of the relationship between dyslexia and being teased at school were investigated by using a fictitious situation about a boy or girl with dyslexia who is laughed at in class to elicit narratives from the children. The results of this study suggested that children with dyslexia are vulnerable in situations where other children can see that they are low achievers. These children disliked teachers who made them read aloud in class, and felt uncomfortable finishing their work much later than their peers. Most of the children in the study (83%) had been teased because of having dyslexia, and 25% reported that they were frequently teased and bullied (p. 421). According to Snowling and Stackhouse (1996), the most comprehensive data available on dyslexia focuses on the school-aged child; however, the majority of this data defines the characteristics of children with dyslexia but fails to describe the emotional consequences of living with the disorder.

Various studies have investigated the ways in which young people with dyslexia cope and how the disorder can impact self-esteem (Riddick, 1995; Humphrey & Mullins, 2002; Humphrey, 2001; Ingesson, 2007; Alexander-Passe, 2006). Riddick (1995), using semi-structured interviews analyzed how children and their families coped with dyslexia. Twenty-two children with dyslexia between the ages of 8 and 14 and their mothers were interviewed. All children attended mainstream schools full time and supplemented their studies with several hours

per week of specialized tutoring at a dyslexia Institute. Mothers were asked 36 questions covering areas of early development, support at home and school, identification of dyslexia, specialist support, the effects of dyslexia on the child and family, and expectations for the future. The children were asked 28 questions about their home life, the type of support they had at home, the difficulties they experienced as a result of dyslexia, the support they received at school and at the dyslexia institute, their overall view on dyslexia, and how others perceived them.

All mothers said that their children had been happy and well adjusted until they started school, and 77% mentioned that their children showed increased tears and tantrums, depression and withdrawal, and physical symptoms like bedwetting, and reluctance to go to school after struggling with academic work. Some students in the sample stated that the move to "junior school" (middle school) had been a critical period due to higher standards of literacy. Survival in the classroom became a frequent theme during interviews. Many children mentioned how stressful exams and tests were due to the time constraints and their difficulty in accurately reading the questions. Over 70% of the children in the study said there were things that they dreaded doing in school, such as dictation, spelling tests, and reading aloud in class. The majority of the children spoke about feeling humiliated when they finished assignments last or got the lowest score on spelling tests, and the pressure they felt to keep up with their peers.

The effects of dyslexia on self-esteem and self-concept were analyzed by Humphrey and Mullins (2002) as a part of a PhD thesis. In the first of two reports,

the authors explored the relationship between dyslexia and the way students perceive themselves as learners. In the first part of a larger study, Humphrey and Mullins measured personal constructs and attribution for academic success and failure in three groups of students. One group consisted of children with dyslexia at mainstream schools (24 students), the second group was made up of children with dyslexia attending a specialized setting for specific learning difficulties (26 students), and the third was a control group of children without learning disabilities (23 students). Participants in the study were between the ages of 8 and 15.

The study reported that children with dyslexia in both the mainstream and SpLD groups saw a much stronger association between reading ability and intelligence than the children in the control group. This implies that children with dyslexia believe that when one is good at reading, one is intelligent and vice versa. Since children with dyslexia are more likely to be poor readers, they are likely to perceive themselves as unintelligent. In terms of self-esteem and self-concept, this finding suggests that until reading is corrected for these students, they will perceive themselves as unintelligent. The dyslexic mainstream group also perceived a much stronger association between being hardworking and intelligent, and since children with dyslexia are often labeled stupid or lazy, this perception may also lead them to see themselves as less intelligent than their peers.

In a second study, Humphrey (2001), further explored the relationship between self-esteem and dyslexia. Data were collected using teacher rating-

scales and self-reports from students. Results were compared from three groups including a group of students with dyslexia in a mainstream setting, students with dyslexia in specialized specific learning difficulties schools, and a control group without dyslexia or other learning disabilities. All children were between the ages of 8 and 15. The results suggested that the dyslexic-mainstream and control group were both less likely to display boastful behavior. The students in the control group were significantly less likely to display timid behavior, to avoid situations of possible stress, to continually ask for help, and to remain at the fringe of a group than the students with dyslexia. The control group was less likely to daydream than the dyslexic-mainstream group. The self-rating scales also showed that the dyslexic-mainstream group reported significantly lower levels on a popularity scale.

While the studies outlined above focused on self-esteem, three studies also analyzed levels of anxiety in individuals with dyslexia (Carroll & Iles, 2006; Riddick, Sterling, Farmer, & Morgan, 1999; Tsovili, 2004). Carroll & Iles (2006) aimed to determine whether students with dyslexia in higher education had higher levels of anxiety, and concluded that students with dyslexia had levels of anxiety that were significantly higher than those of students without learning disabilities. These students felt anxious not only in academic tasks, but also in many social situations. Riddick, Sterling, Farmer, & Morgan (1999), looked at self-esteem and anxiety in adult students with dyslexia. Self-esteem was measured in sixteen university students with dyslexia and their matched controls using a self-esteem inventory. Anxiety was measured by using the state-trait

anxiety inventory. The study results showed that the group of students with dyslexia reported feeling more anxious and less competent in their academic achievements than the control group.

Although two of the studies investigating anxiety focused on college students with dyslexia, one study (Tsovili, 2004) analyzed the relationship between language teachers' attitudes and the anxiety levels of adolescents with dyslexia. It aimed to determine the role that anxiety plays in the lives of adolescents with dyslexia by including a school perspective that emphasized the role of the teacher. The participants included two groups of Greek adolescents and their language teachers. The first group consisted of 68 adolescents with dyslexia ranging from ages 13 years 5 months to 16 years 5 months and their language teachers and the control group included 68 adolescents without dyslexia of average academic performance also ranging in age from 13 years 5 months to 16 years 5 months and their language teachers. The students were given the State-Trait Anxiety Inventory for Children translated into Greek while the teachers filled out questionnaires. It was found that students with dyslexia reported higher levels of reading anxiety than those without dyslexia. This suggests that students with dyslexia see reading as a threatening and stressful experience and that reading difficulties not only cause anxiety in adolescents with dyslexia, but they may determine their perception of the world. The findings of this research also suggest that high reading anxiety among adolescents with dyslexia may be related to a phenomenon of learned helplessness. Many of the

students felt that they had no control over the outcome of their actions and this could have severe implications in other areas of their life.

The majority of studies analyzing the experiences of students with dyslexia have also emphasized the role of parents and teachers, but two studies paid particular attention to the perspectives of adolescents and young adults (Ingesson, 2007; Alexander-Passe, 2006). Ingesson (2007), a Swedish clinical psychologist, investigated how young people with dyslexia "experienced school in terms of well-being, educational achievement, self-esteem, peer relations, and belief in the future" (p.574). Seventy-five individuals between the ages of 14-25 were interviewed in a semi-structured fashion. In the areas of well-being and success in school, most participants felt that their feelings of well being had been low in elementary school, and even more subjects felt uncomfortable in middle school. In secondary school, the majority felt "good" or "very good". One girl stated that she loved secondary school because she could finally do the things she was best at (she had chosen to enroll in a florist program). Under the category of self-esteem and belief in the future, 40 percent of participants felt that dyslexia negatively influenced their self-esteem "quite a lot" or "very much" and in terms of optimism for the future, those who had dropped out of school (even those who were unemployed) were more optimistic than those who were still in school. In regards to dyslexia's impact on their choice of curriculum and occupation, the majority of students had chosen a vocational program in secondary school, and only 13 percent chose a course-load of purely theoretical material. All the employed participants had blue-collar jobs such as "shop

assistant, carpenter, or stockroom worker". When discussing peer relations, most subjects felt that dyslexia did not affect their relations with others, and felt that friends had made school bearable. One participant said, "the best moments in school were the breaks." Conversely, almost a third of the sample claimed to have been bullied and teased for having difficulties with reading and writing, and the more participants felt that dyslexia had negatively affected their peer relations, the lower their feeling of well-being had been in the first nine years of school.

In a related study, Alexander-Passe (2006) sought to analyze the way teenagers with dyslexia cope and how this affects self-esteem and depression, but unlike Ingesson (2007), Alexander-Passe used standardized testing as the sole method of data collection. This was the only study found dealing with coping strategies and self-esteem that involved a sample restricted to teenagers. Three standardized tests for self-esteem, coping, and depression were administered to a sample of nineteen students (12 males and seven females all within their 11th academic year). The resulting data suggested that males and females score differently on these measures and this sample of females scored lower than males on all sub-measures of self-esteem, including academic and general self-esteem. When data from all standardized tests were combined, results suggested that teenage dyslexic females use emotional and avoidance-based coping (which include frustration, lack of confidence, self-doubt, sensitive to criticism, etc.), which resulted in moderate depression, while males with dyslexia apply task-based coping (such as being expressive, pro-active, persistent, and

stubborn, etc.), which resulted in minimal depression. These findings suggest that females with dyslexia need special focus on self-esteem as an integral part of intervention programs.

Several studies analyzed successful intervention methods for students with dyslexia that incorporated issues of self-esteem (Burden & Burdett, 2005; Burton, 2004; Long, MacBlain, & MacBlain, 2007). Burden and Burdett (2005) analyzed factors associated with successful learning in students attending an independent special school for boys with dyslexia. In this study, fifty boys between the ages of 11 and 16 were interviewed, given a Likert-scale, and the Myself-As-Learner-Scale (MALS). The data collected was used to analyze the pupil's levels of depression, learned helplessness, and self-efficacy. The researchers found that the students from this sample had highly positive attitudes toward learning and concluded that if mainstream schools are to become "dyslexia friendly," they will need to establish whole school policies that foster strong feelings of self-worth and self-determination in all students.

In another study, Burton (2004) evaluated the efficacy of self-esteem groups for adolescents with dyslexia. Two pilot self-esteem groups were developed for boys with dyslexia in a mainstream secondary school. The first group consisted of five eighth graders and the second of five ninth graders. The participants attended a dyslexia self-esteem group once a week for six consecutive weeks, and involvement in the group was entirely voluntary. Teachers recommended students they felt could benefit from the experience, and parental consent was required. During the last group session, students were

given the opportunity to evaluate the experience. Upon completion of the program, all participants stated that they had enjoyed taking part in the groups. Several students mentioned that they found it valuable to be able to speak to others with similar difficulties. The boys claimed that participating in the group had helped them feel more confident in dealing with and coping with dyslexia, and had taught them how to talk about themselves with greater ease. When interviewed a year later, the boys still felt that the experience had been helpful and mentioned that after the program, they began to believe in themselves more, and became more positive in their thinking.

Long, MacBlain, & MacBlain (2007) also focused on self-esteem when they published a case study about an adolescent student from Northern Ireland named Matthew who was diagnosed with dyslexia. The study described a model of intervention implemented at Matthew's school that consisted of two major steps. First, compensatory strategies were put in place at the school to help Matthew overcome his difficulties. A whole-school training was set-up to educate the staff on dyslexia and each school department re-examined their policy on the marking of spelling and grammar to ensure consistency. Teachers were asked to refrain from asking Matthew to read aloud in class, and a whole school policy was adopted so that Matthew and other students with similar needs would not have to take dictated notes or copy large amounts of text from the board (handouts would be given in advance). Second, Matthew was taught strategies that would empower and enable him (such as reflecting on his own learning style). A mentor was appointed from the staff to meet with Matthew twice a week

in order to let Matthew share his thoughts and ask questions, and a cross-curricular approach was implemented at the school to teach study skills and test-taking techniques.

Six months later, findings from standardized testing found that the discrepancy between Matthew's reading score and his cognitive ability was no longer significant. Matthew reported that he now saw school as a "more caring place" (Long, McBlain, & McBlain, 2007, p.129). Although he still had difficulties with spelling and with the completion of his homework, and felt resentment at having to work harder than others, overall, his parents described him as being much happier and more relaxed. The holistic approach to intervention used in Matthew's case highlights the idea that if schools want to include students with dyslexia, they must "view themselves as validating communities, which effectively address issues of self-esteem and self-efficacy" (Long, McBlain, & McBlain, 2007, p.132).

It can be concluded, when analyzing the studies reviewed here, that children with dyslexia are at a greater risk of developing poor self-concepts and low self-esteem. This may not only affect their academic performance and interactions with their peers, but can alter the way they make sense of the world. All three studies on intervention methods that successfully addressed self-esteem concluded that if schools are to effectively include students with dyslexia, they must become validating communities that attend to issues of self-worth and self-determination. It is evident that living with dyslexia can greatly impact a student's self-perception and his or her perspective. It will be important to

determine the extent to which adolescents with dyslexia in the general education classroom are affected by their disability and how this impacts their perceptions of themselves and the world.

Statement of the Problem

While dyslexia's effects on self-concept, self-esteem, and other areas of emotional development have been analyzed by the studies reviewed above, there is a paucity of research focusing on the unique experiences of adolescents learning in the general education classroom in the United States. All studies investigating adolescent dyslexia and its various effects on development, including those that focused on mainstream education settings, were of international origin, with the majority of research having been published in the United Kingdom (Riddick, 1995; Humphrey & Mullins, 2002; Humphrey, 2001; Alexander-Passe, 2006; Burden & Burdett, 2005; Burton, 2004) Several researchers have interviewed children with dyslexia and emphasized either the role of parents and/or teachers (Riddick, 1995; Tsovili, 2004; Long, MacBlain & MacBlain, 2007). The present study aimed to further understand the perspective of students living with dyslexia in order to gain new insight.

A number of studies have included adolescent subjects; however, their findings do not solely reflect the experiences of adolescents since the views of younger and older individuals were not teased out when results were presented. One study focused specifically on the way in which teenagers with dyslexia cope and how it affects self-esteem (Alexander-Passe, 2006), but the researcher opted to use standardized tests as the single method of data collection. The

current study was designed to take into account that students with academic histories of struggle would be more comfortable with research methods that did not simulate or evoke negative past academic experiences. Responses were elicited from teenagers with dyslexia in an open-ended fashion in order to determine what patterns spontaneously arose from their experiences.

Adolescence may be the final opportunity to intervene before students with dyslexia simply give up. The fact that it is the last chance for schools to empower individuals who may have already developed negative self-concepts makes it crucial that researchers provide new insight into these student's perspectives and life experiences. Although many of the studies available on the topic provide valuable information, the majority of studies reflect the experiences of young people in other nations. This makes them less useful when attempting to understand the views of students with dyslexia in the United States. The experiences of students growing up in an American education system are bound to be unique when compared to those of students in countries like the UK, Ireland, India, Italy, Greece, The Netherlands, and Sweden. If effective intervention programs are to be created for students with dyslexia, it is of great importance that those involved have a clear understanding of the students' perspective.

By interviewing adolescents with dyslexia in the United States, the present study aimed to further understand this population's unique experience. It has been estimated that 5-10% of the US school population has dyslexia (Karande et al., 2007). Fostering greater understanding of the experiences of adolescents

with dyslexia has great implications for society at large. Students with dyslexia who feel devalued and isolated at school may turn to disruptive or deviant behavior as a way to seek the attention they crave (Heiervang, Stevenson, Lund, & Hugdahl, 2001). Defining the emotional effects of living with dyslexia and how these affect academic success and influence other areas that contribute to quality of life can lead to the development of more effective intervention programs. These could lessen or prevent the negative behaviors that many of these students develop when their needs are not being met. If schools can foster feelings of confidence and good self-esteem in students with dyslexia and further understand their perspectives, they will not only impact the lives of students with learning disabilities, but will positively affect all students in the general education classroom.

CHAPTER II

METHOD AND PROCEDURE

Method

Participants

Participants in this study were eight children between the ages of 13 and 16. The sample included three 13-year-old participants, one 14 year-old participant, one 15 year-old participant, and three participants who were 16 years-old. In terms of gender breakdown, two participants were male and six participants were female. All participants were identified as having a specific language impairment or learning disability in reading and spelling in the presence of a nonverbal IQ within normal limits, and in the absence of confounding diagnoses.

The method of recruitment involved contacting school districts in the states of New Hampshire, Massachusetts, and Maine. School administrators from a variety of middle schools and high schools were contacted via telephone and e-mail. Information regarding the study, letters to parents, consent, and assent forms were distributed to schools, specifically to school principals, speech-language pathologists, and other special education professionals both in person and via e-mail. Of the schools contacted, six schools agreed to facilitate

the research process. After obtaining permission from school principals, speech-language pathologists identified children who were eligible for the study and sent letters, consent forms, and assent forms to the parents of identified students. The letter sent to parents included the purpose and procedure involved in the study, as well as contact information for the researcher, and the UNH Institutional Review Board. Letters written to school administrators and parents, and parental consent and child assent forms can be found in Appendices B, C, D, and E. Four schools, two middle schools and two high schools in Southern New Hampshire and Maine, yielded subjects with signed consent and assent forms.

Materials

All interviews with participants were recorded using an audio digital recorder. A Tascam DR-1 Portable Digital Recorder was used and all data were transferred to the researcher's password-protected laptop computer. The same guiding questions were used for all semi-structured interviews (see Appendix F).

Procedure

Participation in the present study involved one semi-structured interview with the examiner. Interviews took place during non-academic periods and the most appropriate times were determined by the speech-language pathologists and or case managers at each school. The duration of interviews ranged from twenty minutes to forty-five minutes depending on the flow of the interview and the personality of the student. Participants were interviewed individually in private

locations including the speech-language pathologists' offices and available conference rooms within the school. Prior to beginning the interview, students were read the child assent form orally by the examiner and it was reiterated that all interview data would remain anonymous. During the interview, some questions were reworded by the examiner to the language level deemed appropriate for the student and follow-up questions often varied from student to student. Upon completion of the data collection process, all audio recordings were transcribed and ready to be analyzed for patterns in a qualitative fashion.

Data Analysis

Data analysis procedures loosely followed Miles and Huberman's protocol (1994).

Step 1: Data reduction. Interview data were transcribed, organized, and its mass reduced so that it contained relevant information. All participants were assigned pseudonyms.

Step 2: Data display. In this stage, a chart was developed to help in the identification of systematic patterns or themes. Possible themes were highlighted and color-coded along with supporting data to facilitate organization.

Step 3: Drawing conclusions. What the analyzed data meant was considered and its implications were assessed for the research question posed: What did these interviews say about the lived experience of adolescents with dyslexia?

CHAPTER III

RESULTS

Results

Data were analyzed to explore and highlight patterns found in interviews with eight students between the ages of 13-16 diagnosed with specific language impairment or a learning disability in reading and spelling. Participants included 7th graders Brendon, Sarah, and Andrew, 8th grader Allie, 9th graders Kaitlyn, Bailey, and Annie, and 10th grader Natasha. The findings were divided into two categories: internal factors that impact adolescent students with dyslexia (such as deficits and feelings within the student) and external factors that affect them (such as peer interactions and the role of teachers and parents). Many of these themes were found to co-exist for students with dyslexia. For example, low self-esteem (an internal factor) could have been influenced by negative interactions with peers (an external factor).

Internal Factors

Feelings in School

Participants were asked how they felt about school on the whole. Based on their answers, it appeared that students associated two major factors with their overall satisfaction in school. They frequently mentioned their social network

and the level of help they received when answering this question. Three students referenced their social life and relationships with other students when answering how they generally felt about school. Four students mentioned the help they had access to or received in their answers. Bailey and Kaitlyn both felt that their feelings about school had changed now that they were in high school. Bailey described high school as fun because she was able to spend time with friends and be around a variety of people. When asked how she felt in elementary and middle school Bailey said, "I didn't like middle school and I didn't like elementary school. I'm liking it more now than I did back then. People are maturing more than they were back then and I'm getting along more with everyone." For Bailey, negative interactions with other students seemed to strongly dictate her feelings about school in the past. Despite continuing to struggle with reading, she seemed to have a more positive outlook in high school due to a higher level of satisfaction with her social life.

Kaitlyn, much like Bailey, explained that being in high school was enjoyable because "you get to see more of your friends and you get to hang out with your closest friends. Like at school you have a big diversity of people to hang out with." It seemed that for her, too, the ability to participate in a varied social network influenced her perception of school. Kaitlyn, also referenced the theme of access to help when comparing how she felt in middle school and elementary school. She responded by saying:

I found that [in] middle school I was getting a lot more help. Now that I look back to like elementary school I just got pretty much pushed aside if I needed

help and I just passed with like Cs and stuff...There wasn't like enough people there or whatever and they wouldn't be able to help [us]. But then [in] middle school, it feels like I was able to do more stuff and get the help that I needed.

Kaitlyn felt that she received more help in middle school and high school and it seemed that the level of support she had access to significantly affected her feelings about school.

Sarah, one of the youngest participants, stated that she usually felt positive about school. Like Kaitlyn, she referenced the association between having a social network and access to help and her level of satisfaction in school. She said, "I know I have a lot of good friends that like if I ever need help with something or like teachers they'll always help me and stuff." Sarah mentioned several times during her interview that she felt comfortable at school because her two sisters, both also in middle school, could always be counted on for assistance.

The two oldest students, Annie and Natasha, both cited access to help in their answers about their feelings in school. Annie answered by saying, "I feel good. I get a lot of help by the teachers and it's getting easier." Similarly to Kaitlyn and Bailey, for Annie, increased assistance in high school led to more positive feelings about school. On the other hand, Natasha stated that her experiences were better in elementary and middle school because she "got to sleep longer. And the teachers like helped [her] more." Like Natasha, another student, Allie, also found that her experiences in the earlier grades provided her with greater access to help and with a less intimidating environment.

When asked how she felt about the transition from elementary school to middle school, Allie said “I was really nervous. I was like terrified about here.” She enjoyed elementary school because “it was like smaller cause [she] was used to smaller groups—small, like classes.” Her fear of participating in larger groups and bigger classes made middle school more challenging for Allie. In addition, increased social demands could have lessened Allie’s overall satisfaction in middle school given her very reserved personality.

Two students, both in 7th grade and the only male participants, immediately brought up reading when asked about their feelings in school. Andrew mentioned preferring middle school to elementary school because in elementary school he didn’t enjoy “being pulled out of class in the middle of math to [go to] reading.” Brendon answered by saying, “I feel like I struggle sometimes about certain classes because um, one of the things I struggle with is like reading and I usually read a lot slower than the other people. In like language arts I’m always behind in a lot of my work because I can’t read as fast as other people” For these students, being pulled out to receive services and persistently lagging behind were salient factors when describing their overall school experience.

It could be speculated based on these findings that the factors that determine general satisfaction in school may vary between genders. While all the female students referenced social networks and levels of support as relevant patterns when describing their feelings about school, the two males in the sample immediately began to cite the impact that feeling singled out had on their perception of school. Both the stigma of being pulled out of class and of

continually lagging behind could have highlighted the feeling of being different for these boys in a way that was not as evident in the female participants when answering this particular question. It could be hypothesized that the boys in this study struggled more with accepting that they needed help while the girls became frustrated when they felt they did not receive enough help. Annie summed up this difference when she made the following statement during her interview: "I think girls show it a lot differently because they're not afraid [to ask for help]. Guys are just all tough and they think that they can handle it all by themselves, cause they don't want to get made fun of and stuff."

The majority of female students strongly valued the social networks that they concurrently viewed as support. For the male students with dyslexia, the stigma of asking for and getting help may have led to challenges in establishing fundamental social relationships, and this, in turn, could have resulted in less positive feelings about school.

Early Impressions of Diagnosis

During their semi-structured interviews, students were asked to recall if and when they were told they had a learning disability and when reading and spelling became a struggle for them. Feelings about these experiences seemed to be more salient for some students than for others. An interesting pattern arose when the students who were able to describe their impressions about being diagnosed were compared to those students who were less able to articulate and recall those feelings. Those students who were less aware of their early struggles

and who could not quite recall the period of time when they were diagnosed generally seemed to be less likely to be self-advocates, less articulate when explaining their strengths and weaknesses, less accepting of their disability, and seemed ill-equipped to set realistic goals for the future.

Two students, both in high school, remembered their struggles in early elementary school quite clearly. Kaitlyn seemed to be cognizant of her differences at a young age. She said, “I knew I needed help in elementary school but I never really either asked for help or anything because my parents weren’t that great at what we were doing either.” From a young age, she was aware that her parents shared some of her deficits and knew that she needed to seek help outside the home when completing schoolwork. She specifically remembered the challenges of reading in first grade and her feelings about staying back in Kindergarten. When discussing why she repeated a grade, Kaitlyn said, “I don’t know if they were like first grade words or not but we kept getting ‘because’ and like stuff like that [for] spelling words. They were like huge words and I remember not spelling those at all—not getting at least close to those in Kindergarten at all.”

Like Kaitlyn, Annie distinctly remembered when she was told she had a learning disability. She said,

I was in third grade and I had just moved. I went to [a new] school for like half a year and the time I was there like they were really far ahead and I couldn’t tell time and I didn’t know how to read and I didn’t know how to make vowel sounds and all that stuff and they tested me and they wanted to keep me back because I didn’t know how to do any of it.

When asked if she understood when they told her she had a learning disability, Annie replied:

Yeah, because it was really hard for me. Because I didn't know how to do the things that other kids were doing. So it was hard, and I was just like, 'Why can't I do this?' And like I always had to ask for help and the other kids were just like, 'Oh, I'm done' and it took me like forever. So, they like told me that I had it. It was a lot easier [when] they knew that I had it [than] when they didn't know I had it.

For Angela, being diagnosed with a learning disability provided her with some relief because she could finally name the challenges she had been experiencing and she felt that she would be able to receive the help she needed.

In the case of Brendon, a 7th grader diagnosed in the 6th grade, the diagnosis occurred more recently, and therefore, he had a heightened sense of how he felt when he was told that he had a learning disability. During his interview, he was visibly down when describing the events that led to his current diagnosis. He said,

They told me that last year... There was around a month left of school. They told me that um, I'm gonna start having to go up to 'ed techs' to um, get some more learning help...I went home and I cried because I felt like I was getting picked on and I was sort of scared cause I didn't want to be in it... Like I've seen people get picked on for being in special [education]. Like my brother, he's in special [education]. And I've seen him get picked on before where it led to violence. And then I was afraid that that was going to happen to me.

Kaitlyn and Annie felt that receiving services at a young age made them more comfortable with having a disability now that they are high school students. Both students noted that they had made significant progress in their reading and spelling over the years and mentioned intervention strategies that they use consistently. Brendon, who found out more recently, seemed to still be coming to terms with his disability and often made statements that showed that he was struggling to accept himself, such as when he said, "Sometimes I make myself feel really bad that I have to be like this."

When asked when their difficulties in reading and spelling began, two of the students answered that they have struggled “forever.” Both Andrew and Bailey could not remember a specific time when reading and spelling began to cause the anger and frustration to which they became accustomed. Andrew said, “It’s always been hard,” and when asked to describe his feelings about beginning to get extra help, Andrew stated that he felt “different than everyone else.” Bailey said that reading has “been the same since forever” and that she has always been much slower at reading. When describing her experiences in elementary school, Bailey pointed out that she “absolutely hated reading” and writing and that she used to get frustrated and give up, but now in high school she felt that reading and spelling became easier due to increased practice. All participants mentioned that they “hated” reading in elementary school and several students stated that they continued to avoid reading as much as possible.

Allie stated that she is “still learning how to read better” but could not specifically remember being told that she had a learning disability. She recalled that reading became increasingly difficult in the 4th grade and remembered getting help then. She had difficulty describing the reason why she needed extra support: “I think it’s because of the words. I had a hard time saying words. And more like—it was hard to like figure out what words were so I didn’t like want to do reading.”

Sarah, and Natasha were the least articulate and the most inconsistent when talking about their challenges in reading and spelling. When asked if reading had been hard for her in the past, Sarah said, “No, not really. Like if

there's like a big word I don't understand I try to like sound it out or just like guess what it is. But sometimes it is really hard if I don't get it." She seemed to be more comfortable discussing her difficulties as the interview unfolded and as she became more at ease but seemed hesitant to fully accept that reading was challenging for her. Sarah did not recall ever being told that she had a learning disability and seemed to understand that the way she learned was different than the way other students learned, but lacked enough insight to fully explore the subject. Natasha, a 10th grader with significant challenges was also unclear on when she was told she had a learning disability and was unable to articulate her challenges throughout the interview. She answered by saying, "I think it was when I was younger. Like, I don't remember."

During their interviews, all students were asked what they hoped to do in the future. The students who seemed least aware of their disability and who did not vividly retain early impressions of their diagnosis seemed to set the least realistic goals. Allie, a student with considerable challenges and short-term memory deficits who has always struggled academically felt confident that after high school she would go to college and become a doctor. Sarah, who often seemed hesitant to accept that she struggled with reading and spelling said, "I obviously have to go to college" and answered that she wanted to become an animal doctor, and Natasha, who also struggled to describe her deficits and could not recall being diagnosed felt that she would also go to college despite considering dropping out of school in the 8th grade.

Kaitlyn and Annie were the only two students who mentioned that they would need to seriously prepare and seek assistance in order to go to college. Additionally, while all participants mentioned that they ask for help when a task is difficult, the three students with the most vivid impressions of their diagnosis, Kaitlyn, Annie, and Andrew, were also the only students who cited becoming more independent as a goal or as a sign that they had made progress.

It is plausible to think that being aware of their challenges at an early age can help students become more introspective and therefore, be better equipped to evaluate and describe their own strengths and weaknesses. Those students who were more aware of the characteristics of their learning disability seemed more likely to seek assistance as a means to empowerment and to apply a variety of strategies in order to succeed academically.

Challenges in School

When asked how having a learning disability influenced their performance in school, all students gave answers that indicated that having dyslexia does indeed affect student performance in a variety of ways. Some of these deficits were specific to reading and spelling, and others transcended into other areas including comprehension, memory, pragmatics (or the social use of language), and test anxiety. The challenges noted by participants could impact their performance in a variety of tasks and were frequently interconnected. For example, comprehension, or as students described it, “understanding,” was cited

as an area of significant struggle for all participants, but the reason behind the struggle may have been different from one student to the next.

Sarah noted that she frequently struggled to understand her peers in social situations. During her interview, she asked for clarification several times because she did not understand a specific word. When asked whether her parents were patient when helping her with her homework, she became confused and asked what the word patient meant. She struggled to fit her definition for patient (a sick person) into a different context. Like many students with learning disabilities, Sarah seemed to struggle with multi-meaning words, and this could have greatly impacted her in social situations where students say “sick” and “sweet” when they mean very good. She said, “ If I don’t know the word, like what it means, like I have trouble knowing what other things mean—like what other kids talk about.” Her limited vocabulary and difficulty understanding figurative language have also affected her comprehension in social situations and her performance in the classroom.

Bailey found that comprehension and note-taking were areas that affected her school performance on a regular basis. According to Bailey, “It just makes things more harder to like understand and it takes you more to like write something down cause you want to make sure you write it down correctly.” For Bailey, comprehension seemed to be less isolated to the understanding of vocabulary and more related to her note-taking ability in the classroom. She seemed to have difficulty understanding the material in the classroom because all of her efforts were focused on the task of encoding her notes properly. While

other students may have been able to quickly take down notes and revert their attention back to the material being presented, Bailey often spent all her class time attempting to jot down notes.

Like Bailey, Brendon noted that comprehension was also an issue that affected his ability to perform in the classroom for similar reasons. He said, “two classes that it affects is computer class because I type slower—because I listen to the words slower and I, um, and I struggle in language arts because I have a hard time listening.” Much like struggling to take notes, for Brendon, focusing on his spelling while attempting to type made computer class particularly difficult. In language arts, his most challenging subject, Brendon often found it hard to listen because he was always behind on his work. The combination of holding material in his memory while attempting to spell his notes, and then trying to make sense of them was often overwhelming for him and frequently led to daydreaming. Like Brendon, all participants referenced having trouble focusing in class for long periods of time and several students noted that they wished that they did not quickly resort to daydreaming in their toughest subjects.

Two students referenced their deficits in reading specifically when talking about school performance. Allie said “ it’s sometimes difficult if I don’t know like the words in the passage.” For Allie, not knowing the word sometimes meant not knowing the meaning of the word and at other times meant that she was unable to decode the word. Similarly, Andrew felt that having a learning disability predominantly affected him in reading and language arts classes. He said that “in the rest of the classes, probably not so much. Not unless you have to read a

huge packet, and then it slows [you] down.” Unlike the other participants, these two students seemed to be less aware of the broad impact that struggling to read and spell could have on general school performance.

Academic performance was not solely affected by specific deficits within the student but often impacted by social and emotional issues as well. Kaitlyn felt that even after making tremendous gains in her reading and spelling, having a learning disability continued to impact her on a social level when it came to classroom performance. The fear of ridicule while reading aloud prevented her from fully participating. She said, “Volunteering to read—I still don’t do it. Even though like I can tell since I’ve been in Wilson [that] like I can actually read faster than some of the kids in my class, I still don’t like reading outloud.” All participants mentioned that their fear of reading aloud was a major obstacle in the classroom.

Like Kaitlyn, Sarah also felt that the fear of making a mistake in front of her teachers and her peers affected her participation but not just when reading aloud. Sarah answered, “When I raise my hand and when I get the answer wrong, I feel like sort of weird, cause it was like so easy that other kids get it like right off the top. So that’s a little frustrating and sort of embarrassing, too.” Bailey, who often lagged behind in class due to her meticulous note-taking, said that her “essays would be marked up because [she] used to spell words wrong and [she] wouldn’t really want to write anything.” The fact that her spelling errors were made more apparent with red pen markings continually highlighted for Bailey that no matter how long she worked on her papers and how hard she tried, she still

could not spell. All participants were often afraid of taking risks and of participating in the classroom due to a fear of ridicule and a tremendous fear of failure.

For Annie, reading, memory deficits, and test anxiety were particular challenges. She said that she “got like a D in social studies because it was all reading and remembering and tests and stuff.” She went on to say, “some people take mental notes and I can’t do that. I have to like write it down and I can’t really remember a lot of stuff, so I put it in my agenda like [my teacher] said.” Memory deficits seemed to be common among all participants. During their interviews, Sarah and Allie both continually struggled to retain the question that had just been asked of them in short-term memory. Other students mentioned the challenge of holding on to information while taking notes and Natasha explained that she often had to hear material several times in order to remember it. Like Annie, many students reported feeling highly anxious during quizzes and tests and that the feelings escalated as they watched their peers complete their exams rather quickly.

In addition to experiencing challenges in the general curriculum, Annie mentioned the particular struggle of studying a foreign language. While she always feared speaking in front of the class, she felt that it was especially difficult in a foreign language course. She said, “It’s hard in English and I’m trying to learn a foreign language, cause I take Spanish. So, it’s different cause you don’t know English and now you have to learn a different language when you don’t

know this first one as well.” Annie felt tremendous pressure to pass her Spanish classes because she knew that it was required in order to get into most colleges.

It can be deduced from the answers given by these particular students that adolescents with learning disabilities struggle in a variety of areas that can impact academic and general school performance. In addition to difficulties in decoding and encoding, many of the students noted differences in their comprehension of vocabulary, their understanding of figurative language, their ability to listen and attend for extended periods of time, their memory, organizational skills, note-taking and study skills, stress management, and test anxiety.

There were several examples during interviews where students were unable to describe some of their struggles or when they did not correlate specific challenges with having a learning disability. Natasha explained that having a learning disability was extremely stressful and seemed to focus more on her feelings about the disability than on understanding her strengths and weaknesses. She seemed to continually focus on the anger and frustration that she felt when she “didn’t get it”. What some students described on the surface as “boring” or “annoying” were in fact often areas of struggle in the classroom. Natasha mentioned having failed her art class in the previous year because she found the class “boring.” When given time to explain what her experience was like in art class it turned out that the class was very fast-paced and that there were many directions given that Natasha missed, making the class challenging for her despite the subject matter. Other students, including Andrew and Allie,

described classes such as social studies as annoying. When probed for more information, Andrew explained that he found not being able to keep up annoying while Allie found it annoying when she did not receive enough help from the teacher's aides in social studies. During these interviews, it was evident that students with dyslexia face a number of challenges in the classroom and that they are often unable to clearly articulate or explain their feelings in difficult situations.

Self-Esteem

In addition to determining how dyslexia affects them in the classroom, the students in this study were asked to consider whether or not their learning disability has affected their self-esteem. Four of the eight students directly answered that they had low self-esteem. The remaining four students did not feel that their learning disability resulted in low self-esteem but their answers throughout their interviews often indicated that it certainly had an effect. The major themes that came up when students discussed how they felt about themselves were fear of failure, the constant comparison to typical peers, and effort.

It is speculated that for these students with dyslexia, experiencing failure since a young age led to deeply internalizing those failures. One example of this was the extreme fear of reading aloud that all participants noted. Some students, despite being aware that they were now better readers, still refused to read aloud for fear of experiencing those negative feelings again and for fear of being teased

by peers. Kaitlyn stated that having dyslexia “doesn’t really bug [her],” but then clarified by saying “not anymore.” She stated that her self-esteem was affected more in 7th grade when she had to do a lot of reading aloud in the classroom. Kaitlyn noted that she still refused to read aloud and yet did not think that her self-esteem continued to be affected. It seemed that even when students with dyslexia improve in their areas of deficit they are still unable to let go of the negative feelings associated with those tasks and associated with their failure.

When Allie was asked about the impact of dyslexia on her self-esteem she answered, “It really hasn’t affected me.” But then went on to say, “sometimes I feel left behind because I can’t read some of the words. I get really nervous cause I don’t like to read in front of the class. I don’t like to speak in front of a room of people.” Like Kaitlyn, negative experiences in the past have led Allie to fear not only reading aloud in the classroom, but public speaking in general, yet Allie did not associate feeling self-conscious and different with having low self-esteem.

In addition to highlighting fear of failure, Allie’s response also referenced the theme of comparison to typical peers. She mentioned feeling left behind as did all other participants. Andrew also answered that having a learning disability did not affect his self-esteem but went on to say, “I still have friends and I still do everything that normal kids do.” Throughout his interview, Andrew made a distinction between himself and “normal” children. Despite claiming that he did what all “normal” children do, he stated that having dyslexia made him feel “different than everyone else.”

Brendon was asked about the impact of a learning disability on his self-esteem. He answered, "Sometimes I make myself feel really bad that I have to be like this." Having been diagnosed just one year before his interview, Brendon seemed to be struggling with accepting his new identity. He continually noted how different he felt and how he wished that there was something he could do to change his circumstance. Despite being extremely resourceful and bright, Brendon seemed to focus immensely on his new label in special education.

Bailey also tried to keep up with typically developing students and struggled when she could not perform at their level. When Bailey was asked about her self-esteem, she answered that having a learning disability made her feel frustrated and angry with herself. She replied, "I used to not like coming to school as much. Like fifth through seventh I didn't like coming to school." Bailey was asked to describe what was happening in grades fifth through seventh and she answered, "I just couldn't keep up with everyone else, with the reading, and it was—I had to take it slower. It just kept on going from making me frustrated to really angry about it." The theme of peer comparison came up in all interviews whether students mentioned keeping up with reading, writing, note-taking, participation, homework and test completion, or grades. Based on these answers, it can be surmised that students with dyslexia often compare themselves with their typical peers and begin to feel badly about themselves when they continually fall short.

In addition to mentioning their fear of failure, and the continual comparison to peers, many students also saw a connection between their effort and their self-

esteem. Sarah, who in the beginning of the interview answered that she generally felt content in school, described how her learning disability affects her self-esteem as follows:

It affects myself by like not actually trying...I try to make my mom proud, but like it seems like I never can...Some of my teachers say, 'If you try, it's better than like not trying.' Like you get more credit for trying than not trying. But sometimes it's hard to try, because you don't understand it, and you don't want to get it wrong.

The concept of effort and motivation came up when discussing self-esteem with several other students as well. Annie, a 9th grader, directly answered that dyslexia affected her self-esteem because she felt that she did not handle things well when she became overwhelmed. She said, "I don't have that high of a self-esteem when it comes to tests and quizzes and a lot of work that gets put on me. I do get really stressed out and I just say forget about it and I just don't think about it anymore." Annie seemed to define self-esteem as confidence and highlighted that she lacked confidence in herself and often felt badly that she was prone to giving up in times of stress.

When Natasha was asked whether having a learning disability affected her self-esteem she simply answered no, but later in the interview she stated that she often avoids asking people for help. She went on to say, "I always think everyone hates me pretty much. Like I just think I make bad impressions on people." When asked to explain why someone would dislike her she replied, "Cause they think I don't try." While remembering specific situations in the past where others made assumptions about her level of effort she said, "I remember teachers being like, 'Well, you're not even trying. I'm only going to help you when

you try.' And it was like, OK, I don't get it. Like I kept reading it and was like, 'I don't get this.' And that's why I got frustrated and was like, 'OK, I'm not doing it.'" Later on, when Natasha was asked what strategies she uses when facing difficult situations she answered, "Mostly give up."

Sarah, Annie, and Natasha all seemed to feel some shame about the way they handled their disability and their level of effort in difficult situations. Given that many participants admitted that they often give up and can be prone to daydreaming, it is plausible that they may be perceived as lazy and may begin to identify with that label and in turn, feel negatively about themselves.

The issue of self-esteem in students with learning disabilities is one that has not often been addressed, yet in a small sample of eight students, it was clear throughout interviews that some of the negative situations that these students have experienced in the past have stayed with them and continue to affect their view of themselves and of the world.

Interactions with Peers

Closely related to the subject of self-esteem is the issue of bullying in adolescents with learning disabilities. Participants were asked whether their learning disability affected their interactions with peers and sometimes more specifically whether they were ever bothered or bullied because of their differences. Much like their answers about self-esteem, many students responded that bullying had not been an issue for them but went on to make comments that showed that they continually feared being ridiculed by peers.

When Allie was asked whether she ever experienced or witnessed bullying related to having a learning disability, she answered, "I don't know. Maybe, maybe not." It was unclear whether her previous answers detailing her fears of reading in front of the class may have resulted from negative experiences with teasing in the past. Annie answered the question by saying, "some kids, when I read, I read kinda slow, so, they're like 'Come on, hurry up a little bit' but they're like all my friends so I know they're not teasing me because I don't really know how to read that well." Despite the fact that Annie seemed to know that this teasing was not malicious she went on to say, "But I do get uncomfortable when I have to orally read something in front of the class--in front of somebody. That's definitely one of my biggest fears that I have, is getting up in front of somebody."

Andrew, a 7th grader, was asked whether having difficulties in reading and spelling affected how he got along with other students and he replied, "Sometimes." When asked more specifically if it ever led to bullying he answered that it had in the past. He described the situation by saying, "Sometimes they would say it to my face and sometimes they would say it behind my back." Andrew explained that this would make him mad but that most of the time he "blew it off." For Andrew, bullying occurred more frequently in elementary school and seemed to be less of an issue in middle school. Andrew stated that at his middle school, there were "more people around to stop them. More kids are friendlier now and know what it was like and just don't think it's right. They would say things like, 'Stop ' and 'It's not that funny,' and stuff."

Brendon was surprised at the way his peers have behaved in middle school. Like Andrew, he has found that the students in his middle school have been more supportive and understanding than students in the past. He answered by saying, "Actually, I was really expecting this year that I was going to get picked on, but the weird thing is, it feels like I made more friends, because they understand the way I am and they understand that I really didn't have a choice. "

Unlike Andrew and Brendon, Kaitlyn described several instances in middle school where her disability led to harassment from her peers. When asked if having dyslexia affected her relationship with other students she said:

Probably because like you could be thinking about something to write and they look on your paper and go 'Wow! You don't know how to spell that? That's such an easy word.' It does get frustrating because some people will like know the word and all of that, but like in 7th grade we had to read in groups once and then I was just trying to sound out a word in my head and they would just keep telling me them and they got frustrated—like really quick. And then they would laugh.

During her interview, Kaitlyn became visibly distressed and cried while describing her feelings about these negative situations in middle school.

Several participants openly discussed having been victims of teasing and bullying while others seemed to believe that bullying was something that they could control. In other words, several students answered in a way that presented teasing as something that students could prevent if they were friendly enough or if they worked hard enough at their friendships. Bailey stated that she was never bullied because she "didn't let [her] reading affect [her] friendships or anything." Sarah felt that her disability did not affect how she got along with other kids

because she is “a really friendly person, and [she] [likes] to spend time with [her] friends.”

It is plausible to surmise that if students with learning disabilities feel that bullying is within their control, they are more likely to internalize feelings of inadequacy when they are picked on since they are apt to think that they could have prevented those negative interactions. Even those students who stated that they have not been bullied in the past feared being ridiculed when reading aloud in front of peers. It seemed that many of the participants had different definitions for negative interactions with peers. Some seemed to think that bullying meant that violence was involved while teasing, although hurtful, was not considered bullying.

External Factors

Advice for Peers

During their interviews, students were asked to determine what other children need to know about students with learning disabilities. In their answers to this question, several students referenced bullying without being prompted to do so. Allie answered by saying, “It’s hard, because sometimes you can’t—it’s difficult sometimes for people because they can’t say a word...they don’t want to get picked on or something. But if I don’t know a word, I’m trying my hardest to get it.” Her answer alluded to the fact that she felt that other students have not understood that she is trying her hardest and that typical students are likely to pick on students with learning disabilities. Much like Allie, Bailey, also referenced teasing when she said, “I’d tell him that he needs help with it [the kid] but you

shouldn't pick on him because it's his way of learning." It seemed that Bailey also made the assumption that typical students are likely to pick on students with learning disabilities. When Sarah answered the question and said, "They have feelings. They're the same. Like we're all the same except for different," she may have been referencing the idea that typical kids hurt children with learning disabilities under the assumption that they are different and do not have the same feelings as them.

Kaitlyn wanted her peers to know how difficult it is for students with learning disabilities and Annie answered by saying:

I would say that they don't know what it feels like to not be able to physically be able to do something and if they did have a chance and to really think about it like if someone didn't really know how to read or talk that well, just think of how much harder life would be, like not being able to do that. And like, put their self into somebody else's shoes who doesn't have what they have.

Additionally, Natasha stated that students with learning disabilities "can't learn as fast as they do, so they shouldn't get frustrated." Kaitlyn, Annie, and Natasha all gave advice that illustrated their belief that typical students lack their perspective and that they feel misunderstood on some level.

Overall, when answering this prompt, all participants gave responses that signaled that their peers perhaps show a lack of understanding of their disability and that participants may have experienced teasing, frustration, and a lack of support from some of their peers.

The Role of Teachers

All participants were asked to describe the perfect teacher during their interviews. This group of students with learning disabilities described the perfect teacher as someone who checked in to ensure that his or her students were caught up, that the students comprehended the material and were able to keep up, and that the students understood what was expected of them. In addition, the participants seemed to greatly appreciate knowing that their teacher was willing to listen and that he or she would not give up on their learning. These students, like most, also wanted teachers to make learning exciting, engaging, and active.

Two students mentioned that the perfect teacher would be able to ensure that all students were satisfied with the class pace and that students were able to keep up. Allie said, "They make sure you are doing OK and you're all caught up with everyone else. And make sure you don't get lost when stuff's happening." Similarly, Bailey felt that knowing when to pick up or slow down the pace was also a characteristic of the perfect teacher. She said, "She'd have to know when to slow down during class or speed up when everything is getting boring." The majority of participants mentioned feeling rushed in the classroom and often felt that their teachers did not notice if they were lagging behind.

Bailey also felt that the perfect teacher should be "really loud and exciting." Andrew agreed that the perfect teacher would have a gregarious personality. He said, "He would kind of joke around but the jokes would help you. [Teachers] should do class work but do some games and fun activities that have to do with what you're studying too. Do games and projects to help you learn

things.” Like Bailey and Andrew, Brendon felt that his perfect teacher would also have an element of activity and excitement. He said that if he could design the perfect teacher he would make him “sort of like a gym teacher” because he enjoys playing sports and always being active. Many of the participants seemed to imagine that in the ideal classroom, learning would be much more lively, hands-on, and active. Given that these students frequently mentioned that they had trouble sitting still and listening for long periods of time, it seemed logical that some of them would make the regular classroom more like physical education if they could.

Several students mentioned that the perfect teacher would be able to reword information when necessary, present information clearly, and give clear expectations in the classroom. Brendon stated that his best teachers are able to take a sentence that he does not understand and “put it in a different way.” Natasha said that her favorite teacher is easy to listen to and explains things in away that lets her understand. Annie felt that one of the best things that a teacher could do was set clear guidelines for her students. She stated that when teachers were tougher and made the classroom highly structured, she was able to know what was expected of her and what she needed to learn in order to succeed. When describing the teachers who challenge her she said, “They don’t just like slip the grade by you. Like you have to work for it.”

Three students viewed the perfect teacher as someone who would be understanding, compassionate, and who would be able to teach creatively in order to include all learners. Kaitlyn felt that the perfect teacher would certainly

be “someone that you can talk to.” Sarah described the perfect teacher as “really nice” and said that, “if the kid needs help they should find a way to find out how to make this person, he or she understand. Like in ‘lit lab,’ I didn’t understand the word but like when I saw a picture, it like helped me more.” The perfect teacher for Sarah would be someone willing to think outside the box and willing to find different modes to teach her students.

When Natasha described the perfect teacher she had someone in mind. According to her, having a teacher who would not give up on her made all the difference in 10th grade. Although Natasha considered dropping out of school the previous year, her English teacher seemed to have made a tremendous impact on her. When asked to describe the perfect teacher, she said:

My English teacher. She just always tries to help and she won’t let you fail. She doesn’t let me fail. So like she’ll do everything she can to help me and she’s not hard. She understands. She’s not there to be our friend but she kind of is cause she’s like understanding. If we’re having a bad day, she’ll listen to what’s wrong.

Despite English being Natasha’s most challenging subject, she stated that she was actually enjoying going to English because she was finally learning something.

Advice for Teachers and Parents

The students were asked what advice they would give to teachers and parents working with students with learning disabilities. The overall theme that emerged when students were given this prompt was that adolescents with dyslexia feel extremely rushed and pressured to perform at the same level as

their peers. The majority of participants referenced typically developing children at one point or another and compared their performance to those children. For example, the students said in their answers that they could not read as well as their peers or as fast as their peers. They mentioned not being able to take notes like their peers or to complete their exams as promptly as their peers. Several students even mentioned that their parents should not expect them to learn as quickly or to get good grades like their peers. The pressure to measure up is one that seemed to haunt these students on a daily basis. As Sarah stated, "I try to make my mom proud, but like it seems like I never can." Others felt that their teachers did not appreciate or notice their efforts, but despite these challenges, all participants showed a great deal of appreciation for the extra help and support that they have received.

Allie was one of several students who emphasized the struggle of feeling rushed. She said, "Don't make people rush. Don't make kids rush through the passages if they have like a reading issue." She went on to explain that she often felt rushed even in her reading lab where she went to get extra help. She pointed out that she enjoyed the reading group much more this year because the new teacher significantly slowed the pace. Going along with feeling rushed, many students wanted to highlight to teachers and parents that they should expect that students with learning disabilities will work at a much slower pace. As Kaitlyn explained,

It just takes a little bit longer because I know that I like, I'll take an hour longer on my homework most of the time. They all say, 'It's a half an hour long.' Some kids will be like, 'That's so easy' and I say, 'It takes me an hour to do it!' It might still be easy, but it still takes me long. I write really slow and like taking

notes, its just like I can't do it word of mouth because I don't like spelling the wrong things but then I write really slow so it takes forever. And then they'll give you a time limit to do things sometimes so that way they can talk about it, but that just stinks because I'll still be writing things sometimes when they're trying to discuss it. So you're like never finished when you get stuff like that to do.

Kaitlyn explained that students with learning disabilities have many disadvantages in the classroom. While teachers often determine or announce how long an assignment will take, students with learning disabilities know that in reality it will take them much longer to complete. When students are given a time limit in the classroom to complete a task before moving on to discussion, Kaitlyn felt that students with disabilities often miss the discussion and have to spend additional time catching up

Brendon also mentioned that students with disabilities work at a slower pace. He said, "They need to understand that kids that struggle work a lot slower than others and um, probably won't get as good as grades as the other ones unless they really study and work hard." Brendon felt that teachers and parents should lower their expectations for how their children will perform academically. Given that Brendon was recently diagnosed, he may have been accustomed to failing grades since he lacked the supports and services that may have allowed him to succeed.

Three students wanted parents and teachers to know how challenging it is for students with learning disabilities to comprehend material and to learn quickly. Sarah emphasized that parents should accept their children and understand that it is hard for them in school because they have a different learning style. She said, "it's sort of like putting the parents' shoes into the kids' shoes...and like

seeing like what the kids are actually trying to like say to the parents but the parents don't understand. It's like hard for kids to understand. Like, there's different ways---people are different." Sarah seemed to feel a lot of pressure to do as well as her sisters in school.

Annie and Natasha emphasized that they have difficulty retaining information and they often need to cover material for much longer than their typical peers. Annie explained this by saying,

They need to know that it's a lot harder for kids to learn stuff and when you—I don't know, you tell them to do something and then they don't remember like the first couple of times, like you can't get stressed out--and like if I'm taking a test and I ask for help, it means that I need help because I don't know how to do it. And some teachers are like, 'Well, we just went over that yesterday' and I was like 'Yeah, but I don't really remember that well.' So some of them, they don't understand that well and some teachers don't even really know and then I ask for help and they're just like, 'I can't really give it to you.' It makes it harder.

Like Annie, Natasha also felt that teachers and parents often become stressed or frustrated when she struggles to understand new material as quickly as they would like. She gave the following advice:

They shouldn't get frustrated if we don't get something right off cause it's not easy for us to understand what's going on. [Adults who don't understand] try to rush learning and if they understand they'll keep going over it but they'll just go over it once and be like, 'OK, go do something else.' And you don't get the other thing. If they're teaching something new, just like go over it more than they should.

Many of the students felt pressured to get through material quickly so that the adults helping them would not become frustrated and give up on them. Andrew also felt tremendous pressure. His advice to parents and teachers working with students with learning disabilities was, "Push them, but don't push them to the

point that they go crazy.” All participants seemed willing to work hard with the right support, but occasionally, they simply wanted a break.

Feelings about Support

Participants were asked to describe their feelings about the supports and services that they get during their interviews. The majority of students were grateful for the help they receive despite having experienced challenges with specific teachers, programs, and sometimes even parents. Based on the answers given by these students, it can be said that teachers play an immense role when determining whether a student will embrace his or her supports and services.

Allie stated that she was enjoying ‘reading lab’ much more in 8th grade because the new teacher “Makes sure you understand it before you go on.” When asked how she feels about the extra help she gets she said, “I feel good about it. Like, I know I needed it but I’m being a better reader over time. Sometimes I didn’t want to be in reading lab, but I like it [now], because I’m learning.” Bailey, who was transitioning out of the reading program at her high school, was confident that she had made enough gains to do well next year but was sad to be leaving the program because she will miss the teacher. Andrew was also appreciative of the extra support he received. He said, “I like it. I guess because it helps me understand things that I don’t always understand.” Kaitlyn was glad that she had been in the Wilson program since the first grade. She

answered by saying, "Since I've been in Wilson for so long, like I can tell that my reading's improved and like all my spelling so it's a lot easier for me to do stuff." Brendon stated that he occasionally feels upset that he has a learning disability but still could see the benefit of getting extra help. He said, "Sometimes I feel down because I feel I wish I wasn't this way but then I understand that if I didn't get extra help I'd be failing, which I'm passing a lot of my classes." Angela appreciated some of the accommodations that she receives as part of her support program. When asked if she minds having to leave the class when taking tests she said, "Not at all. I like to go out and have it quiet cause a lot of people do their stuff faster than I do. It takes me a lot longer so like when I'm in class and I'm working on something I can't concentrate cause everybody else is already done."

Natasha was extremely grateful for the support of her new English teacher and attributed much of her progress in the last year to her teacher not allowing her to fail and believing in her. She mentioned being worried about how she would do in English the following year with a new English teacher. She predicted that she would definitely fail.

While receiving special education services, especially in adolescence, is often associated with stigma, all participants in this study seemed to be grateful that they had access to help. All students understood that without the assistance they have received, they would be in a much worse position. As Annie stated, "I honestly think that I would be really bad right now. High school is really hard and

it's really stressful so if they did not find that [I had a learning disability], then I'd probably have a lot harder time."

CHAPTER IV

DISCUSSION

Discussion

Using qualitative methodology, this exploratory study was designed to understand and describe 8 adolescent students' perceptions of the impact that dyslexia has had on their lives and experiences. Based on the students' answers, findings indicate that dyslexia affects all dimensions of an individual's life, including academic, social, emotional, and psychological areas of functioning.

Feelings in School

When reflecting on their feelings in school, three students referenced their social life and relationships with other students and four students mentioned the help they had access to or received in their answers. It was speculated that those students who had the most positive outlooks when asked how they felt in school did not solely focus on their disability, had strong social networks, and perceived that they had access to a great deal of help. Although only two male students participated in the study, a gender difference was noted in how male students

answered this particular question when compared to females. Both males immediately mentioned their struggles with reading when asked about their overall feelings in school and highlighted how different they felt while the female participants referenced the two themes outlined above.

The students' answers to this question illustrated that while having a disability greatly impacts how they feel about school, the majority of students may place greater importance on the strength of their social networks in adolescence. These results are partly supported by Ingesson (2007), who reported that the more subjects felt that dyslexia had negatively affected their peer relations, the lower their feeling of well-being had been in school. This finding has significant implications for students with learning disabilities since they tend to experience more social difficulties than their typical peers (Klassen & Lynch, 2007). Overall, if students can view school as a safe haven and can develop strong social networks, they will be more likely to attend and less likely to feel helpless socially and academically.

Impressions of Diagnosis

Feelings about receiving the diagnosis of dyslexia seemed to be more salient for some than for others. It was hypothesized based on the findings that those students who were less aware of their early struggles and who could not quite recall the period of time when they were diagnosed generally seemed to be less likely to be self-advocates, less articulate when explaining their strengths

and weaknesses, less accepting of their disability, and seemed ill-equipped to set realistic goals for the future. This could have been the case for a variety of reasons. An earlier diagnosis could have meant more time for a student to accept his or her identity as someone with a learning disability. The majority of participants in high school noted that they had not come to terms with having a disability until leaving middle school. Those students who had clearer impressions of their diagnosis perhaps received a better explanation of their disability and a better explanation could have potentially led to enhanced self-awareness. On the other hand, the students with vivid impressions may have simply been naturally more insightful.

Overall, it could be posited that students who are given a better explanation of their disability at a young age generally have a clearer understanding of who they are, and perhaps this could lead them to become better self-advocates, more articulate when explaining their wants and needs, more independent, and therefore, be more likely to succeed.

Challenges in School

It can be deduced from the answers given by these particular students when asked how dyslexia impacted them in school, that adolescents with learning disabilities struggle in a variety of areas that can affect academic and general school performance. In addition to difficulties in reading and spelling, many of the students noted deficits in their comprehension of vocabulary, their understanding of figurative language, their ability to listen and attend for

extended periods of time, their memory, organizational skills, note-taking and study skills, stress management, and test anxiety. The deficits and struggles outlined by these participants are supported by various studies (Riddick; 1995; Humphrey & Mullins, 2002; Humphrey, 2001; Ingesson, 2007; Alexander-Passe, 2006).

The students often shared many of the same challenges but the way an area such as comprehension affected one student may have differed from how it impacted another. Some students struggled with understanding vocabulary, others with figurative language, some could not comprehend the overall meaning of text because their focus was one decoding individual words, and others were expending their efforts on note-taking and were, therefore, unable to extract the meaning of a lecture. This has important implications if schools are to meet the needs of students with learning disabilities. When it is listed in a child's profile that "comprehension," is an area of weakness, it should be noted that this could manifest itself in a variety of ways and could be the result of more than one area of deficit.

In addition to their inherent deficits, it was found that students often struggled academically due to socio-emotional factors. Many students avoided the task of reading aloud for fear of being ridiculed by peers and mentioned giving up on writing due to the embarrassment of having their work marked up in red pen by teachers. Negative experiences that made students feel shame and embarrassment often stayed with them and led to struggles in motivation. This finding is supported by Singer (2005) who reported that children with dyslexia are

vulnerable in situations where other children can see that they are low achievers. If educators are to enlist practices that increase quality of life for students with learning disabilities, the classroom activities that bring these students so much anxiety and embarrassment should be re-evaluated. For example, graded class participation, timed spelling tests, and tasks involving reading aloud are areas that need to be modified or eradicated in order to meet the needs of a diverse school population.

Self-Esteem

Four of the eight students directly answered that they had low self-esteem. The remaining four students did not feel that their learning disability resulted in low self-esteem but their answers throughout their interviews often indicated that it certainly had an effect. It was found that all students felt shame, embarrassment, or wished that they could change something about themselves. It was speculated that these students with dyslexia were more likely to have low self-esteem because they all continually compared themselves to typical learners.

When students with dyslexia attempt to keep up with other students and repeatedly fall short, it is bound to have an effect on how they feel about themselves. Ingesson (2007) reported that 40% of 75 participants with dyslexia reported that dyslexia negatively affected their self-esteem “quite a lot” or “very much ” and this was consistent with the results of this study, although with a much smaller sample.

Students with dyslexia are unique in the world of special education in that unlike students with multiple disabilities, their deficits are not as apparent and less physical. Because of this “invisible” deficit, these students seemed to often be expected to perform and keep up with all other students in the general education classroom. As they frequently experienced situations where their weaknesses were highlighted and where their differences were made apparent, they seemed to internalize those difference and as a result, their self-esteem dropped.

Because students with dyslexia compare themselves to typical peers, it is imperative that they are also involved in activities and programs that highlight their strengths. Intervention programs that address self-esteem and issues of self-worth are vital if students with dyslexia are to improve their quality of life and are to succeed socially and academically. Several studies have concluded that if schools are to effectively include students with dyslexia, they must become validating communities that attend to issues of self-worth and self-determination (Burton, 2004; Long, MacBlain, & McBlain, 2007; Burden & Burdett, 2005).

Interactions with Peers and Advice for Peers

The subject of self-esteem is closely related to the issue of bullying in adolescents with learning disabilities. Much like their answers about self-esteem, many students responded that bullying had not been an issue for them but went on to make comments that showed that they continually feared being ridiculed by peers. Their inconsistent answers may have been the result of several factors.

First, the students may have been hesitant to fully disclose information about a very sensitive and personal issue. Second, their definition of bullying may have been variable. For example, some students felt that teasing, even if hurtful, was not the same as bullying, which seemed to have a more violent connotation. Both male students openly discussed their experiences with bullying in the past and all participants feared being “picked on.”

When asked to give advice to peers, the theme of bullying was one that all students alluded to without being prompted to do. All participants gave responses that signaled that their peers have shown a lack of understanding of their disability and that students may have experienced teasing, frustration, and a lack of support from some of their peers. The prevalence of bullying for these participants is supported Singer (2005) who reported that most participants in that study (83%) had been teased because of having dyslexia, and (25%) of participants reported that they were frequently teased and bullied. These findings are significant and highlight the fact that intervention programs cannot solely focus on students with disabilities but must also focus on creating validating communities and on promoting compassion and acceptance for all students.

Teachers, Parents, Supports, & Services

Participants felt that the perfect teacher was someone who checked in to ensure that his or her students were caught up, that the students comprehended the material and were able to keep up, and that the students understood what was expected of them. In addition, the participants seemed to greatly appreciate

knowing that their teacher was willing to listen and that he or she would not give up on their learning. These students, like most, also wanted teachers to make learning exciting, engaging, and active. When students were asked to give advice to parents and teachers, the overall theme that emerged when students were given this prompt was that adolescents with dyslexia feel extremely rushed and pressured to perform at the same level as their peers. While receiving special education services, especially in adolescence, is often associated with stigma, all participants in this study seemed to be grateful that they had access to help. All students understood that without the assistance they have received, they would be in a much worse position

The students interviewed in the present study were grateful for the help they have received from adults over the years. Many of them noted that they felt pressure to make gains quickly so that adults would not get frustrated and give up on them. It is imperative that students with learning disabilities feel that they are understood, that they will be given enough time to complete tasks, and that professionals will not give up on them. Many students noted that their perceived lack of effort was something that made them feel badly about themselves. It can be speculated that adults have perceived and perhaps even labeled some of these students as “lazy” in the past and that some of these students have internalized that label as a self-fulfilling prophecy. A study by Humphrey and Mullins (2002) noted that dyslexic students perceived a strong association between being hardworking and being intelligent, and since children with dyslexia are often labeled stupid or lazy, this perception may also lead them to see

themselves as less intelligent than their peers. If progress is to be made, it is imperative that professionals and parents not label students with dyslexia before taking the time to understand their unique experiences and insights.

Conclusion

Perhaps the most important finding of the present study is that adolescents with dyslexia are not always how they appear to be. Since these students are frequently unable to articulate or express their true feelings about difficult situations, they often cope by continually trying to cover up deep-rooted deficits. For these participants, daydreaming, when analyzed more deeply was often a result of an overwhelmed system. When students acted out, took a nap in class, and stated that they were bored, or annoyed, it was often done as a tactic to avoid being ridiculed or to avoid facing yet another failure. It seemed that students with dyslexia wanted nothing more than to find something at which they could excel. Intervention programs that address self-esteem and that promote treating the student holistically, and not solely as a reading and spelling deficit, have the unique opportunity to show students with dyslexia that they each have something at which to shine. As Sarah stated, "Like we're all the same, except for different."

Limitations

There were several limitations to the present study including various limitations related to the population of participants. First, an unequal distribution of participants by gender, with the majority of participants being female was not

representative of the typical incidence of dyslexia. Second, a limited geographical area of participant recruitment, and a small sample size signify that the findings of this study are not generalizable to the general population. Finally, the study would have been improved if triangulation would have been employed. In qualitative research, validity is enhanced by including the perspectives of multiple persons (such as interviews with teachers and parents in addition to students). Furthermore, aspects of the method could have been used during the data analysis process, that is, by engaging multiple researchers in coding and labeling arising patterns and themes.

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APPENDICES

University of New Hampshire

Research Integrity Services, Office of Sponsored Research
Service Building, 51 College Road, Durham, NH 03824-3585
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20-Apr-2009

Garcia, Josefine
Communication Sci & Disorders, Hewitt Hall
4 Olde English Village Rd, #109
Dover, NH 03820

IRB #: 4513

Study: The Lived Experience of Adolescents with Dyslexia

Approval Date: 08-Apr-2009

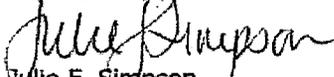
The Institutional Review Board for the Protection of Human Subjects in Research (IRB) has reviewed and approved the protocol for your study.

Approval is granted to conduct your study as described in your protocol for one year from the approval date above. At the end of the approval period you will be asked to submit a report with regard to the involvement of human subjects in this study. If your study is still active, you may request an extension of IRB approval.

Researchers who conduct studies involving human subjects have responsibilities as outlined in the attached document, *Responsibilities of Directors of Research Studies Involving Human Subjects*. (This document is also available at <http://www.unh.edu/osr/compliance/irb.html>.) Please read this document carefully before commencing your work involving human subjects.

If you have questions or concerns about your study or this approval, please feel free to contact me at 603-862-2003 or Julie.simpson@unh.edu. Please refer to the IRB # above in all correspondence related to this study. The IRB wishes you success with your research.

For the IRB,



Julie F. Simpson
Manager

cc: File

Webster, Penelope

Letter for School Administrators

Dear Administrator:

I am a graduate student in the Department of Communication Sciences and Disorders at the University of New Hampshire engaging in a Master's thesis research project. I am investigating the lived experience of adolescents diagnosed with specific language impairment or learning disabilities in reading and spelling. I am searching for participants between the ages of 13 and 16. This is a unique opportunity for your students to offer their perspectives and to bring greater insight to the study of learning disabilities.

The project calls for students to participate in a 45-minute semi-structured interview with me. In these interviews, I will ask them several open-ended questions and will give them the opportunity to discuss their experiences in a safe and private manner. I will maintain the confidentiality of information recorded and obtained during these interviews and any student information will remain anonymous in any reports or publications.

You should understand, however, there are rare instances when researchers are required to share personally-identifiable information (e.g., according to policy, contract, regulation). For example, in response to a complaint about the research, officials at the University of New Hampshire, designees of the sponsor(s), and/or regulatory and oversight government agencies may access research data. You also should understand that researchers are required by law to report certain information to government and/or law enforcement officials (e.g., child abuse, threatened violence against self or others, communicable diseases).

If you are interested in allowing this study to take place in your school and give your permission, please send the enclosed letters and consent forms to the parents of eligible students. Parents and students who choose to participate may then forward those documents to me. They may contact me directly via phone or e-mail to make these arrangements and/or if they have any questions.

I would greatly appreciate your eligible students' participation in this study and I hope you are as excited about contributing to the existing literature on learning disabilities as I am. I look forward to hearing from you and feel free to contact me with any questions or concerns at 603.566.7432 or at my e-mail address (jmgarcia@unh.edu).

Sincerely,

Communication Sciences and Disorders Graduate Student

Letter of Invitation and Consent Form for Parents

Dear Parent:

I am a graduate student in the Department of Communication Sciences and Disorders at the University of New Hampshire engaging in a Master's thesis research project. I am investigating the lived experience of adolescents diagnosed with specific language impairment or a learning disability in reading and spelling. I am searching for participants between the ages of 13 and 16. This is a unique opportunity for your child to offer his or her perspective and to bring greater insight to the study of learning disabilities.

The project would require your child to participate in a 45-minute semi-structured interview with me. In these interviews, I will ask him or her several open-ended questions and will give your child the opportunity to discuss these experiences in a safe and private manner. I will maintain the confidentiality of information recorded and obtained during these interviews and any student information will remain anonymous in any reports or publications.

You should understand, however, there are rare instances when researchers are required to share personally-identifiable information (e.g., according to policy, contract, regulation). For example, in response to a complaint about the research, officials at the University of New Hampshire, designees of the sponsor(s), and/or regulatory and oversight government agencies may access research data. You also should understand that researchers are required by law to report certain information to government and/or law enforcement officials (e.g., child abuse, threatened violence against self or others, communicable diseases).

If you choose to allow your child to participate in this study, please carefully read and sign the enclosed consent form. Please contact me at 603.566.7432 or email me at jmgarcia@unh.edu so that I may collect your consent form.

I would greatly appreciate your child's participation in this study and I hope you are as excited about contributing to the existing literature on learning disabilities as I am. I look forward to hearing from you and feel free to contact me with any questions or concerns at the cell phone or e-mail address listed above.

Sincerely,

Communication Sciences and Disorders Graduate Student

CONSENT FORM FOR PARTICIPATION IN A RESEARCH STUDY

TITLE OF RESEARCH STUDY

The title of this research study is The Lived Experience of Adolescents with Dyslexia. I am Josefine Garcia, a graduate student at the University of New Hampshire conducting this research as a Master's thesis in communication sciences and disorders. My advisor is Dr. Penelope Webster.

WHAT IS THE PURPOSE OF THIS STUDY?

The purpose of this research is to describe and analyze the unique experiences of adolescents with a learning disability in reading and spelling.

WHAT DOES YOUR CHILD'S PARTICIPATION IN THIS STUDY INVOLVE?

Your child will participate in a 45-minute interview. I will ask him or her several open-ended questions about his or her experiences in living with a learning disability and will give your child the opportunity to discuss these experiences in a safe and private manner. I will record data via note-taking and audio recording.

WHAT ARE THE POSSIBLE RISKS OF YOUR CHILD PARTICIPATING IN THIS STUDY?

Your child could become upset when talking about these sensitive issues. If your child is visibly upset during our interview, I will contact you and the school administrator so that you can be aware of the situation. There are no other risks involved with participation in this study.

WHAT ARE THE POSSIBLE BENEFITS OF YOUR CHILD PARTICIPATING IN THIS STUDY?

This study can increase understanding of the experiences of adolescents with learning disabilities that may lead to better prevention and intervention. There are no direct benefits to the participants of this study.

IF YOU ALLOW YOUR CHILD TO PARTICIPATE IN THIS STUDY, WILL IT COST YOU ANYTHING?

This study is being carried out at no cost to you or your child.

WILL YOUR CHILD RECEIVE ANY COMPENSATION FOR PARTICIPATING IN THIS STUDY?

No compensation will be provided for participation in this study.

WHAT OTHER OPTIONS ARE AVAILABLE IF YOU DO NOT WANT YOUR CHILD TO TAKE PART IN THIS STUDY?

You understand that your consent to allow your child to participate in this research is entirely voluntary, and that your refusal to allow your child to participate will involve no prejudice, penalty or loss of benefits to which you would otherwise be entitled.

CAN YOUR CHILD WITHDRAW FROM THIS STUDY?

If you consent to allow your child participate in this study, you are free to stop your child's participation in the study at any time without prejudice, penalty, or loss of benefits to which you would otherwise be entitled.

HOW WILL THE CONFIDENTIALITY OF YOUR CHILD'S RECORDS BE PROTECTED?

I seek to maintain the confidentiality of all data and records associated with your child's participation in this research.

You should understand, however, there are rare instances when I am required to share personally-identifiable information (e.g., according to policy, contract, regulation). For example, in response to a complaint about the research, officials at the University of New Hampshire, designees of the sponsor(s), and/or regulatory and oversight government agencies may access research data.

You also should understand that I am required by law to report certain information to government and/or law enforcement officials (e.g., child abuse, threatened violence against self or others).

Interview information will be collected through audiotape and note-taking. All data (including audiotapes) will be secured in a locked cabinet in my office. I, along with my faculty advisor, will have sole access to the data and results will be reported anonymously. I will collect data on audiotape in order to facilitate analysis and to ensure the accurate transcription of information. Recordings will be destroyed after transcription.

WHOM TO CONTACT IF YOU HAVE QUESTIONS ABOUT THIS STUDY

If you have any questions pertaining to the research you can contact me, Josefine Garcia at 603.566.7432 to discuss them.

If you have questions about your rights as a research subject you can contact Julie Simpson in the UNH Office of Sponsored Research, 603-862-2003 or Julie.simpson@unh.edu to discuss them.

I, _____ CONSENT/AGREE to participate in this research study

Signature of Subject

Date

CHILD ASSENT FORM FOR PARTICIPATION IN A RESEARCH STUDY

TITLE OF RESEARCH STUDY

The title of this research study is The Lived Experience of Adolescents with Dyslexia. I am Josefina Garcia, a graduate student at the University of New Hampshire and my advisor is Dr. Penelope Webster.

WHAT IS THE PURPOSE OF THIS STUDY?

The purpose of this research is to describe and analyze the unique experiences of adolescents with a learning disability in reading and spelling.

WHAT DOES YOUR PARTICIPATION IN THIS STUDY INVOLVE?

You will participate in a 45-minute interview. I will ask you several open-ended questions about your experiences in living with a learning disability and will give you the opportunity to discuss these experiences in a safe and private manner. I will record information by taking notes and tape-recording.

WHAT ARE THE POSSIBLE RISKS OF PARTICIPATING IN THIS STUDY?

It is possible that you could become upset when talking about these sensitive issues. If you are visibly upset during the interview, I may need to contact your school principal and parents so that they can be aware of the situation. There are no other risks involved with participation in this study.

WHAT ARE THE POSSIBLE BENEFITS OF PARTICIPATING IN THIS STUDY?

This study can increase understanding of the experiences of adolescents with learning disabilities that may lead to better prevention and intervention. There are no direct benefits to the participants of this study.

IF YOU CHOOSE TO PARTICIPATE IN THIS STUDY, WILL IT COST YOU ANYTHING?

This study is being carried out at no cost to you or your parent.

WILL YOU RECEIVE ANY REWARD FOR PARTICIPATING IN THIS STUDY?

No reward will be provided for participation in this study.

WHAT OTHER OPTIONS ARE AVAILABLE IF YOU DO NOT WANT TO TAKE PART IN THIS STUDY?

You understand that your consent to participate in this research is entirely voluntary, and that your refusal to participate will involve no prejudice, penalty or loss of benefits to which you would otherwise be entitled.

CAN YOU WITHDRAW FROM THIS STUDY?

If you consent to participate in this study, you are free to stop your participation in the study at any time without prejudice, penalty, or loss of benefits to which you would otherwise be entitled.

HOW WILL THE CONFIDENTIALITY OF YOUR RECORDS BE PROTECTED?

I seek to maintain the confidentiality of all data and records associated with your participation in this research.

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If you have questions about your rights as a research subject you can contact Julie Simpson in the UNH Office of Sponsored Research, 603-862-2003 or Julie.simpson@unh.edu to discuss them.

I, _____ ASSENT/AGREE to participate in this research study

Signature of Subject

Date

Interview Questions

1. How do you feel in school on the whole? How did you feel about school in Elementary/Middle School?
2. Tell me what a typical day in school is like for you.
3. Do you remember when you were told you had a learning disability? If you remember, how did you think or feel then?
4. How much do you think your difficulties influenced your achievements/performance in school?
5. Describe the perfect teacher.
6. What do adults (parents, teachers, etc.) need to know about kids with learning disabilities?
7. How much have your difficulties in reading and writing affected your self-esteem?
8. Do you think your learning disability affects your relationship with other students? Have you ever been bullied because of it?
9. What do other students need to know about kids with learning disabilities?
10. What kind of extra help/support do you get in school?
11. How do you feel about the extra help you get?
12. Do you have any strategies that you use when something is difficult for you?
13. How much would you say a learning disability affects your everyday life?
14. In what kinds of situations at school do you feel the best?
15. In what kinds of situations do you feel the worse?

16. What do you and your friends do for fun?
17. Tell me something that has happened to you that you're really proud of.
18. What would you like to be when you grow up? What would you like to do after high school?
19. If you could give advice to another person with the same academic challenges as you, what would you say?
20. What do you see in your future?