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Process & Research of Dyslexia?
A Book on the Demystification of Dyslexia for Students with Dyslexia

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Abstract

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This paper focuses on the ways in which the demystification of dyslexia for diagnosed or pre-diagnosed students alters their ability to self-advocate. It examines effective ways of demystification and, specifically, how literature can be used to directly teach children how to talk about their difference. This review of research highlights positive and negative effects of providing students with learning disability labels. It also notes that the majority of studies on the subject show that providing students with a label for their learning variations positively impacts self-esteem and academic engagement. However, it is noted that a dearth of children’s literature is available that normalizes students with learning variations. With the intent to design a book that provides a resource for students that addresses social and academic concerns, this paper also explores ways in which design—text formatting, layout, visuals, and audio aids—can help students with dyslexia read independently.

Key Words: Demystification, Developmental Variations, Dyslexia, Self-Advocacy, Learning Disability, Learning Differences
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Introduction and Rationale

What is Dyslexia?

Dyslexia is the most common Specific Learning Disability (DyslexiaHelp, 2017). It affects one’s ability to process written language, often resulting in difficulty with reading, writing, and spelling. Seen as a genetically pre-disposed condition, it usually has a physiological foundation. In fact, both me and my brother have struggled with dyslexia our entire lives. Less efficient neural transmission in the cerebral cortex delays the processes of memorization, organization of ideas and thoughts, word retrieval, and reading comprehension (GreatSchools, 2016). It is typically seen in students of average or above average IQ who often excel in reasoning and problem-solving skills as well as visual-spatial and motor abilities (SmartKids, 2017). In this way, dyslexia could be seen as a different way of thinking and processing rather than a problem. As there is no cure for an alternative thought process, there are proven, effective ways to help students with dyslexia build literacy skills that will help them in mainstream classrooms. Multisensory structured language programs (including the most popular and well-received, Orton–Gillingham) have high success rates helping students with dyslexia develop competent foundations in reading and writing.

Dyslexia should not be a source of shame, and is not a reflection of a child’s actual intelligence. Yet, within our current academic culture, students with learning disabilities, particularly those that fall under the category of dyslexia, have been found to have astoundingly low levels of self-esteem and limited abilities for self-advocacy (Pearl, 2004). In her study of the emotional secondary symptoms in students with dyslexia, Novita (2016) writes that because
“modern society places great value and high expectations on scholastic performance… individuals who struggle with reading tasks...may be vulnerable to emotional consequences such as low self-esteem and high levels of anxiety” (p. 280). When we take a student out of the classroom or provide them with in-class supports, he or she, as well as their peers, take note and form assumptions about themselves and others. What students with dyslexia and their classmates do not notice is the reason behind it (Pearl, 2004). Even when students have supports in place to help them succeed, the resulting lack of self-understanding creates an unhealthy realm in which to learn. With this perfect storm of conditions, students with dyslexia have a decreased motivation to learn (Taylor, Hume, and Welsh, 2010), despite the fact that they are fully capable of mastering the same content as their peers.

We are often told that we need to learn how to advocate for ourselves. But, how can we advocate for ourselves when we don’t know what needs to be advocated?

At Bank Street, during the process of learning to become a better teacher, I have regularly been asked to reflect on my experiences as student and my own educational journey. I directly link my feelings and educative experiences to my journey as a student with learning disabilities.

For many years, I hated school. It was tightly wound with my low self-esteem as a learner. As a child, around the age of five, I defiantly announced “I am not a learning girl. I am a playing girl.” While this story has become folklore in my household, it accurately describes how I viewed school and my own abilities as a learning.

Very early on, as everyone was quickly and excitedly learning to read, I knew that there was something wrong with me. Something worried my parents and something set me apart from
my peers. I had an older brother and friends who did not seem to struggle in the same ways I did. They did not visit numerous tutors after school nor did they subject themselves to the rigorous testing needed for an IEP.

Growing up in the 1990s, labeling students with learning disabilities seemed to be avoided at all costs. Coinciding with the birth of “whole reading” curricula, the trend amongst child academic specialists and psychologists was to include students as much as possible and avoid any specific diagnosis. Teachers hoped that by exposing students to literature reading would just naturally seep into their skill set. Specialists rarely told students that they had one thing or another. Rather, they did what most teachers do: they focused on the child’s strengths and gently worked through the areas that needed growth. Build the child’s confidence and then remedy the issues. For me that meant one thing: avoid the encapsulating term “dyslexia.”

One of my most vivid childhood memories, from around the age of nine, comes just after days of testing. Nine years old is the average age when the majority of students with learning disabilities are finally tested (Novita, 2015). Exhausted and confused, I locked myself in the bathroom and cried for hours while my babysitter tried to lure me out. Something was wrong with me. I just knew it. My parents, arriving later in the evening, joined his attempt to calm me down and convince me that I was not, in fact, “stupid.” Already a skeptic of this kind of academic pick-me-up, I remained planted on the cold tile floor.

The final diagnosis did not help. Rather than pinpointing “dyslexia” as the root cause of my “reading struggles,” my IEP ran in circles around the term. Instead of providing me with a simple label that could help me to define myself, there was a long list of vague difficulties. The document, on which my mother wrote “DO NOT COPY” states that my justification for out-of-
class time was “visual processing concerns as well as issues with visual memory, discrimination and sequencing.” On a separate page, the IEP goes into further detail, “Visual confusion and sequencing issues such as b and d, u and n, n and m, frist and first, thier and their and gardual for gradual are found in her work…she is resistant to writing.”

When reading into the difference between actual visual processing issues and dyslexia they seem worlds apart. I was an avid artist with an acute ability to draw, examine visual differences, and, while contact sports never appealed to me for fear of getting hurt, excellent spatial acuity. Yet, as if a code word, this immediately translated into services to support my dyslexia. This is not an isolated incident. At this time, and to this day, many professionals believed that labeling children with diagnoses such as “dyslexic” would cause them more harm than good.

Starting in fifth grade, I was regularly taken out of the classroom during reading and worked one-on-one with a literacy specialist. While officially called the “resource room,” students nicknamed it “SPED”. Trying to cope with the subtle bullying that existed in my progressive, private school, I turned to laughing at myself and embraced the embarrassment. I started calling myself “SPED” not quite understanding the deeper implications. In middle school, I was one of four students who, instead of taking Spanish, spent a special period working on writing. Naturally, we called it “SPED.”

I carried the shame of having a learning disability with me through college. I secretly took the SATs with extra time and sent private emails to my professors asking for extensions. According to the University of Michigan on their DyslexiaHelp webpage (“Dyslexia at School,” 2017), “accommodations are key to success for you in school. Although frequently
misunderstood as crutches, in reality accommodations level the playing field.” Yet, I still had no real understanding of my disability and instead of advocating for myself, I denied myself accommodations. The more I tried to hide my disabilities—eventually neglecting to tell professors entirely—the more anxious I became. I regularly spent three to four times the amount of time into each of my assignments to receive the same grade as non-dyslexic peers.

Bank Street College of Education, being a progressive and inclusive teaching college, was the first institution in which I felt comfortable enough to tell my story and label myself. It not only became something that I could be open about, but something I was proud of and could use to my advantage. Despite years in progressive, liberal, small schools I never felt as if being honest about my “disability” could benefit me in any way.

But, the question remains: How does one self-advocate when they don't know the cause for which they are advocating?

I spent decades knowing that I was different but without the vocabulary or understanding to advocate for myself. Recently, I was asked why I felt it would be better to know I have a label—labels, after all, often act as a double-edged sword. They can often perpetuate stereotypes or stigmas. However, as soon as I could acknowledge my dyslexia and openly discuss it in my mid-twenties, I finally began to feel free and proud. In response, I tried to paint a scenario:

Let’s say you’re a kid and you have chronic knee pain. When you try to play sports, or participate in P.E. at school, your knee hurts and the struggle to fight through the pain exhausts you faster than other kids. You often try to play with the majority of the class, but it is clear that the physical pain and fatigue of participating like everyone else, without any sort of support is
more debilitating than helpful or fun. So, you acknowledge this and your parents take you to a
doctor. The doctor runs a bunch of tests—she watches you run and jump, checks your reflexes,
maybe even scans your knees from a variety of angles and machines—and comes to a diagnosis.
Rather than reiterating that it is difficult for you to run and jump without pain, the doctor tells
you—plain and simple—that you have weakened ligaments surrounding your knee joint. In a
typical child’s body, the joints would work parallel, in tandem. However, with extra flexible
ligaments, your knees do not.

In order to walk, run, and jump like the other kids, you need to do special exercises to
build strength, retrain your muscle memory to protect your form, and wear a brace to help realign
the muscles, bones and ligaments of the knee. Your physical ailment—your disability—has been
diagnosed and you have been prescribed a series of exercises and supports to help you join the
rest of your classmates without pain. When you go to see other doctors, you can tell them this
diagnosis and they will know how to support you. Most importantly, at school, when classmates
ask you why you need special knee supports, you have a specific diagnosis. You know what to
tell them. There are proven supports that, if done early with regularity, will have lasting effects
into your adult life. The knee pain will not be as inhibiting if helped now. You can advocate for
yourself, because you know what you need to do to strengthen your knee, and to be able to play
with the rest of your class.

Unlike your chronic knee pain, dyslexia affects your academic work. Reading feels
strenuous and it seems to make you more exhausted than your peers after a short period of time.
Even though you have solid, creative ideas, writing takes an enormous amount of energy as well.
Trying to keep up with the rest of your class, you might try to find ways to avoid reading (or
writing, or math). You manage, but your actual progress as a reader is hindered. Your teachers notice this, they intervene, and eventually—if lucky enough—they refer you to a specialist.

Then, you go to a doctor. This doctor does not measure how you run or jump. Instead, they measure how you read, write and think. The doctor administering the test wants to rule in or out all symptoms. Unfortunately, it is something happening in the brain and cannot be so easily traced from a few movements or scans (although technology to do so is advancing). So, these tests take a few more days and require a little more effort on your part. And, these tests require you to engage in the same tasks that feel difficult in school and make you exhausted on a regular basis, it is extremely tiring. Just as when you had chronic knee pain, your parents want to know what is wrong. It is, after all, impacting your quality of life. They want a prescription of efforts and supports that will ensure your academic success.

Then comes the diagnosis. Yet, unlike that time you went to the doctor for chronic knee pain, the doctor can present her findings in two ways: the diagnosis could be presented as a more defined label “dyslexia;” or, a list of symptoms and specific difficulties. Perhaps your doctor shares it directly with you (the child). Or, perhaps they only share it with your parents who can, maybe, distill the information as they see fit. And, perhaps no one will tell you the diagnosis. At school and after school, as with your friend with chronic knee pain, you may begin to see other doctors or teachers and receive special supports—like going to the resource room, going to tutors, or receiving special tools and extra time from your homeroom teacher. Yet, when your peers ask you why, you might not have a solid, simple response for them. Without that solid, simple response neither you nor your peers understand how you are different. Aside from the
social stigma that comes from this lack of information, you are also less informed about what you actually need in order to thrive.

According to resources available through the University of Michigan, to be an effective self-advocate, “you need to know about dyslexia and be able to explain it to somebody else” (“Self Advocate For Your Dyslexia,” 2017). Yet, the delicate nature of the second scenario stems from deeply rooted taboos and cultural values. There is a stigma around learning disorders -- even the word “disorder” itself leads parents to feel as if something is wrong with their child-- and it is hard to find a relatively quick resolution, and it correlates so directly with what we consider important in our culture: standardized academic ability. According to Novita (2016), “Our modern society places great value and high expectations on scholastic performance. Therefore, individuals who struggle with reading tasks as a basic skill to determine academic achievement may be vulnerable” (p. 280). When academic achievement is low, we put students at risk of undermining their self-worth, their intelligence and their true ability. What are we left with? A biased perspective (Taylor, Hume & Welsh, 2009, p. 191).
Literature Review

Over the past twenty years, researchers have investigated the secondary effects of dyslexia. Researchers have been particularly interested in the impact of dyslexia on self-esteem, social-identity, anxiety, and the social-emotional needs of students diagnosed with learning disabilities such as dyslexia (Novita, 2016; Casserly, 2012; Jodrell, 2010; Glazzard, 2010; Taylor, Hume & Walsh, 2010; Dervishi, Shehu & Zhilla, 2015; Riddick, 2000). Throughout their education careers, through undergraduate and graduate programs, students reported issues of anxiety and low self-esteem that became increasingly permanent as children grew into adulthood. While this negative impact typically isolated itself to scholarly environments, it occasionally bled into general living (Novita, 2015). Novita (2015) specifically compared the self-esteem and anxiety of students with and without dyslexia. However, the root cause of these secondary symptoms is unclear. Her results concluded that there is a wide range of variables when it comes to the increased likelihood of students with dyslexia having higher rates of anxiety. However, “it can be argued that children with dyslexia develop higher anxiety and lower self-esteem in certain contexts” (p. 280) such as school. Likewise, Jonathan Glazzard (2010) reports that “found that pupils with dyslexia both in mainstream schools and in special units were more likely to display timid behavior, avoid situations of possible stress and continually ask for help or reassurance than learners without dyslexia” (p. 63).

Academics have a fiercely contested debate over whether or not using disability labels, such as dyslexia, benefits students. Some researchers argue that labeling students perpetuates social stigma that has been historically attached to labels, and thus build walls around students—ultimately going against the purpose of inclusion movements (Jodrell, 2010). One strong belief
is that the label emphasizes the differences and negative bias of students with learning disabilities (Taylor, Hume & Welsh, 2009).

On the other side of the argument, researchers study the benefits of providing a student with a label. They state that only by being more open about labels and normalizing their use can we increase tolerance. Levine (2002) believed that when students have limited control over their understanding of self-- be it their name or neurological wiring-- they fall subject to social ridicule (p. 319). The social stigmatization that has historically occurred, did so without the open use of labels (Riddick, 2000). And, labels, themselves, “encapsulate a disability” (Jodrell, 2010). Furthermore, another argument for the use of labels is that they can open the gates to resources, opportunities, and awareness that are not available without one (Gillman, Hayman and Swain, 2000; Lauchlan & Boyle, 2007).

Recently, a small but growing amount of research has been done on the specific social impact from the child’s perspective on labels. Again, researchers fall into two camps: pro-labeling and con-labeling (Jodrell, 2010). Some have found that providing a student with a label influences self-esteem negatively, placing students in an “out-group” (Jodrell, 2010; Abrams; 1990). A wealth of literature exists that points to secondary symptoms of low self-esteem, academic frustration, and poor achievement. However, more recent researchers have found that while anxiety and feelings of shame were common among dyslexic children, students with dyslexia tended to have positive child-teacher and parent-teacher relationships as well as higher levels of self-esteem when accompanied by a supportive, open environment (Dervishi, Shehu & Zhilla, 2015).
Riddick (2000) found, however, that when students were not formally labeled with dyslexia, they were given alternative labels by their peers, educators, and parents. These informal labels were often associated with being unintelligent or lazy. And, unsurprisingly, those informal labels led to significantly larger negative impact on the self-esteem of students with dyslexia. The understanding that came with the specific, technical label of “dyslexia” was welcomed as a result (Taylor, Hume & Welsh, 2010).

What both educators and researchers have noticed is that students with limited self-advocacy skills and limited information about their dyslexia were more likely to develop low self-esteem and anxiety. Levine (2002) writes in his section of demystification in *A Mind at a Time*, “Kids need to know themselves, and they need to know what to work on to help themselves. They need and deserve to understand clearly the reasons for any academic problems” (p. 277). Cynthia Pearl (2004), a former resource specialist for elementary age students, wrote the article “Laying the Foundation for Self-Advocacy.” In it, she discussed the impetus and progression of a program she started to help students with specific learning disabilities (SLDs) stand up for themselves. She noted that the more she talked “with the students, [she] realized that they didn’t know how to respond” (p. 44) to derogatory comments and, more importantly, did not know what SLD meant. Likewise, they believed bullying peers who teased them for being “slow.” The workshop for her SLD students promoted self-awareness skills and taught them as much as possible about their individual learning disabilities. They learned how to select the information they wanted to share and ended by SLD students presenting to non-SLD peers.
Deborah McCarthy (2007), a student affairs administrator for students with disabilities at the University of Texas at Austin, noted similar inconsistencies. In her article (2007), *Teaching Self-Advocacy to Students with Disabilities*, she writes “in relation to students with disabilities, our American higher education system demands a degree of self-advocacy that students…find daunting and unfamiliar” (p. 11). Even at the university level, students with disabilities continued to lack a real understanding of their learning disabilities and their individual support needs. Connecting with my own experience as a dyslexic student at a highly selective undergraduate college, McCarthy found that students not only lacked the self-advocacy skills but were hesitant to identify themselves—particularly those with less inhibiting disabilities.

For adults, it is easy to access information on how to understand and support their children with dyslexia. Bookstores and libraries stock countless self-help titles that aim to teach parents about specific diagnoses, how to receive resources, and how to decode Individual Education Plans (IEPs). Free resources for parents have also emerged in bulk on the internet. The University of Michigan (2017) has a comprehensive website. The information found there cover a continuum from detailed, neurobiology distilled in layman terms, to tricks to teach your child about dyslexia. It provides information on outside resources, such as what kinds of training to look for in a tutor as well as information on schools that cater to learning disabilities.

**But, what about titles specifically geared toward children with dyslexia?**

Books, both fictional stories and educative non-fiction, not only provide necessary information, but act as mirrors. In 2017, Sara Ackerman wrote a New York Times article entitled, “Mirrors for My Daughter’s Bookshelf.” In the article, Ackerman, a kindergarten teacher with a
four-year-old of her own, describes looking at her home book collection and noticing that only four percent of the books she owned featured protagonists of color, let alone black girls that reflect her own daughter. Ackerman (2017) writes:

In Louise Rosenblatt’s transactional theory of reading, individuals bring their own experiences to a text to understand and draw meaning from it. There are multiple ways to identify with a text… but if a child’s race or ethnicity is underrepresented in books it says something about how those pieces of their identity are valued (Ackerman, 2017, para. 7).

When a child does not see themselves reflected in the literature they read, the message becomes that their life and experience is not valued. Books are not only windows into someone else’s life, but a mirror or depiction of socially accepted reality (Souto-Manning, 2009).

There is limited research on how children with disabilities are represented in literature. The only dyslexia specific study came from Jennifer L. Altieri (2006), who did a comprehensive search of how realistic fiction portrays dyslexia. She found seventy-seven books that featured children with dyslexia, including picture books and chapter books. Of those seventy-seven books, fifty-five female characters struggled with reading versus twenty-two male characters with similar symptoms. She noted that, aligned with the increase in providing children with defined labels of dyslexia, more recent books refer to a child having dyslexia rather than struggles with reading. This signals a shift in how we perceive learning disabilities and the push to normalize language around it.

The majority, over seventy percent, of characters portrayed with dyslexia mirror the secondary symptoms of dyslexia. These books featured students who struggle with academics as well as social skills. Fifty percent of the children portrayed exhibited some sort of behavioral
issue, occasionally perpetuating a bully stereotype (Altieri, 2008). These characters, Altieri notes, work through the issues that accompany dyslexia. She writes that through much of this literature, “readers should have the opportunity to work through their struggles and successfully manage their dyslexia” (p. 87).

This idea of using literature to reflect and address personal and individual struggles has been coined by researchers as bibliotherapy. Starting in the 1990s, academics and professionals began using literature as a way for students to see themselves within a character that overcame a trauma or issue. It provides an opportunity for self-reflection at a distance (Dajevskis, Cappiello, & Crain de Galarce, 2016). According to Sridhar & Vaughn (2000) bibliotherapy could be a helpful tool specifically for students with learning difficulties. With regards to students with learning disabilities, they write:

“studies indicate that bibliotherapy [can be] an overall effective tool for developing assertiveness, attitude change, self-development, and therapeutic gain. Bibliotherapy has also been shown to produce a positive change in self-concept, reading readiness, and achievement” (p. 77).

By seeing a character with similar difficulties produce positive change, children with learning disabilities began to see themselves as more capable of similar achievements. Bibliotherapy has been used to mirror issues and dilemmas and help children independently see ways in which they too can overcome their problems. Altieri (2006) writes that through reflective literature, “children can realize that people are unique and stereotypes are an inappropriate way of viewing the world” (p. 161). These reflections of students with disabilities are crucial. Altieri (2006) writes:
“studies have drawn the conclusion that the use of literature containing characters with disabilities can help children develop an understanding and awareness of the disability. The literature can influence attitudes and feelings toward disabilities and be used as bibliotherapy” (p. 161).

Through literary experiences, dyslexic children who have a label for themselves can begin to identify themselves not only as valuable, but with the power to work through anything they are struggling with. Furthermore, if they have a label that matches a child who is positively portrayed in literature, they can begin to envision themselves as having strengths as well.

However, while realistic fiction is increasingly reflective of children with disabilities, there remains a dearth of non-fiction texts. It is rare to find a resource that provides pre-diagnosed or diagnosed children with the information they need in order to advocate for themselves in any capacity. As providing students with a label for their learning disability becomes more popular, there seems to be a surge in resources as well. Stories such as It’s Called Dyslexia (Moore-Mallinos, 2007), Tom’s Special Talent (Gaynor, 2009), Why Can’t I Read? (O’Hara, 2014) and Knees: The Mixed-Up World of A Boy with Dyslexia (Oelshlanger, 2012) show a trend toward providing students with the information they need to advocate for themselves. Through first-person narratives, these books are beginning to find accessible ways to shed light on the realities of dyslexia in a kid-friendly manner.
Purpose & Use

*Dyslexia?* is a book intended for “kids only,” written in the perspective of the author, myself, as a child. Throughout the book the narrator, Anna, weaves narration and facts together. She provides her easy-to-connect-to experience of having dyslexia with the facts she has learned along the way. In doing so, Anna attempts to blend information and emotional self-reflection. This provides supports for children with dyslexia that enable them to read or browse the book independently, without the help of an adult. Through these avenues, children with dyslexia not only see a reflection of themselves in a book, but they are actively and independently gaining the tools to promote self-advocacy.

With few resources available geared toward children, *Dyslexia?* specifies on the cover that it is “kids only.” While kids and adults will both benefit from reading the book, it is written and designed specifically with children with dyslexia. More importantly, it is intended to be read and reviewed by these children *independently*. The book would be their first step toward self-advocacy: independence. Rather than a one-time read informational handbook, *Dyslexia?* includes activities and information that children can return to both independently and with guidance.

The book itself provides two important features for students with dyslexia. First, the book acts as a reference and informational guide for children. Children, with the help of an adult or independently, are both told and shown what it means to have dyslexia. The book discusses the scientific and physiological aspects of dyslexia through words and pictures as well as the emotional component--the secondary effects-- of having dyslexia. Because the term dyslexia covers a range of abilities and experiences, the book provides questions to engage children
through interactive activities and to help them begin to self-identify with the symptoms and experiences that are relevant to them.

Children are provided with both narrative text and informational text. Adding the collection of stories geared toward children within the eight to ten-year-old age range, Dyslexia? provides an additional, practical mirror. The main character, Anna, narrates informational text through the lens of her own struggle and process of demystification. Woven into the informational and emotional aspects of the book, Anna guides readers through her journey of self-advocacy. In doing so, Anna walks students through steps they can take in their own life.

In addition to the text, Dyslexia? provides children with a space for self-reflection. Throughout the pages, students are asked questions about their own experience which they can answer in a variety of ways, including tracing, writing, and drawing. Children are asked to fill out the book independently, but are reminded at the beginning of the book that needing help is more than okay. Asking for help is a form of self-advocacy. In doing so, children are including others, rather than admitting defeat.

In order to make the book more accessible to students with more inhibiting dyslexia symptoms, the final product will come be available digitally with audio. Independently, these children follow the story and information aurally. Small signals and symbols will show children where on the page to follow so they can do so without the aid of an adult.
Product

Aiming to be a child’s first step toward self-advocacy, each aspect of *Dyslexia?* was carefully crafted specifically for children with dyslexia between second and fourth grades. The design, both illustration and text, attempts to engage children in elementary school while helping them feel independent and promoting their own sense of maturity and ability. The book, over forty pages, including activities and space for reflection, uses watercolor illustrations and text to bring the story and information to life. Additionally, research-backed design elements aim to make the text more accessible for a dyslexic reader. Eventually, audio will be added to aid early dyslexic readers.

The text and illustrations cater to students at the end of second grade through fourth grade. The characters are cartoon-like. The recurring characters have distinct features that make them recognizable and stand-out. For example, Anna, the narrator and protagonist, has wild, curly hair that is pinned with a small pink bow. While her facial expressions change, her outfit and hairstyle remain consistent throughout the story. Additionally, the book includes racial, ethnic, and physical diversity to emphasize the universal nature of the diagnosis.

The target age for this book, nine years, is the average age when children receive their first diagnosis. At this age, there is typically a disconnect between a student’s ability to read (lower reading level) and their maturity (moving toward a more self-aware stage). They often have difficulty finding books that they connect to personally at their reading level. Thus, it is important that the literature available to them not only engages them visually and personally. The text must also show a level of maturity, despite an audience who will typically struggle with reading. The book provides a narrative of a child, roughly around nine years old, who not only
has dyslexia and friends with dyslexia, but has come to a point in which she has found ways to advocate for herself. As she talks about her own experience, she provides kids with the information they need and attitude to demystify dyslexia in order to succeed as a self-advocate. Catering to the maturity of nine year olds, she is honest and open about dyslexia. She does not beat around the bush and even bring in real scientific language to back her claims with evidence.

Many of the features of the book are specifically designed to aid students with dyslexia with reading. Reading black text on a white background or light colors on a dark background, for example, can be more difficult for students within this demographic (AltFormat, n.d.). Similarly, limiting character count per chunk of text from sixty to seventy characters per line with appropriate space can ease eye strain (AltFormat, n.d.). In Dyslexia?, all text is placed on watercolors for the words to be less starkly contrasted. To detract from an obvious “aid,” the softness of the watercolor adds to the aesthetic of the book.

As a book intended for independent use, the audio component will also become crucial. So far, I have not come across any publications for children that include audio. However, in Dyslexia?, students will be able to listen to the words and follow along with the digital or print text. Furthermore, the audio will be interactive. Next to each section of text, students will be able to click the audio button to listen to the exact area of the page of which they want to read. This will allow children to know exactly where they should follow along with the text or, if they cannot yet read the text, give them the satisfaction of gearing their attention toward a specific selection of words. Not only will this benefit their ability to read the book, it will also aid their processing. Because many students with dyslexia struggle with reading, they typically process
auditory information much more easily. Hearing, interacting and seeing the book will provide a more fruitful experience.

The illustration of the book is also designed to provide children with dyslexia visual clues about the words on the page. Using pencil and watercolor on paper, I have drawn simple images that provide clues but do not tell the entire story like a picture book. The illustrations depict the narrator in a variety of scenes, interacting with a diverse group of friends and peers. While the character is meant to be fun and engaging-- she wears a bright purple t-shirt and has wild, curly hair-- she also shows specific emotions to set the tone of the words on the page. For example, when the narrator introduces the embarrassment she can feel when reading to the class on page three, the bright watercolor shows only her sad face with a thought bubble.

While entertaining characters and bright colors will engage and attract children, the medium of watercolors provides both a vibrant and natural look. This veers from traditional ideas of informational guides. Instead, watercolor provides a more “homemade” look, almost as if the narrator had painted the book herself.
Process

The idea of writing *Dyslexia?* came to me during my course on Developmental Variations. I had been reflecting on my own dyslexia throughout my first year at Bank Street in a variety of classes-- ranging from museum education seminars to language acquisition. Then, in Developmental Variations, I began to think about dyslexia beyond my own experience. Looking at the diagnosis from a more clinical standpoint, I started to realize what tools and resources I lacked as a child but needed to become more confident. Along those same lines, I also began to think about why I needed those tools: how would certain resources help me within the larger scope of educational policy and support students to advocate for themselves and meet their expectations. From my own experience and from the course, I noticed a large gap between our school system’s demands and expectations from children with learning disabilities and the resources available to demystify it for them.

This journey of realizations and research led me to my final project: a manual for children about dyslexia. In eleven pages, the small, digital guidebook summed up dyslexia for kids. It included scientific facts about dyslexia, statistics about who has dyslexia, ways to understand your own symptoms of dyslexia, reasons why it is important to understand your dyslexia, and ways to help yourself and speak with others about dyslexia. Beyond building a self-awareness and personal demystification of the learning disability, it provided children with the words and ways of discussing it with others.

A wealth of research led me to ways in which I could provide children with in depth, accurate knowledge that promotes self-advocacy. As preliminary data for my Integrative Master’s Project, I sought information that would give me a foundation of tools to discuss
dyslexia with young students. This would ultimately help me write with them in mind. Beyond this foundation, I sought information about what kinds of aids could be used to help children with dyslexia read independently.

Upon completion, I felt as if my original idea could be pushed further to fill an actual void in children’s literature. As mentioned in my literature review, few fiction books have been written with mirrors of children with dyslexia that actually aim to educate. Self-advocacy was not the primary intention for the books available. Students needed a resource that would both mirror their experience and teach them.

Once I decided to pursue this project as my integrative master’s project, I began to dive deeper into research. As a driving force, I reflected on my own journey and experience with dyslexia in school and developed a set of questions, concerns and fears. These included both questions and concerns I had as a child and the lingering questions I had as an adult created a foundation for research that reflect real life and experience.

Thinking about the purpose of the book itself, I also began to research the idea of literature as bibliotherapy. A method that became popular in the 1990s, a time of turbulent discourse amongst the academic community studying dyslexia, I was specifically interested to see the research of the effects of teaching students with learning disabilities about their disability and the benefits of normalizing a label through literature. Then, after researching for months I began to expand the original informational guide into a book with more narrative. Seeking ways to engage young readers with more scientific and complicated ideas behind learning and thought, I decided to create a young character based on myself who had experienced school with dyslexia and the process of becoming her own advocate.
I transformed the original text in three ways. First, I expanded and broke down the information I originally provided. I sought vocabulary that not only fit the average experience and background of students within the target age range, but I also tried to mold it into honest and accurate information. Second, I created a narrative. Instead of a pure guidebook style of text, I decided to make the narrator a more personal and motivating character. Intertwined with information, Anna provides examples of her own life to which readers can connect. Third, I broke up the text on the pages. The original guidebook provided all the necessary information in eleven dense pages. To really provide an easy-to-follow narrative, illustrated effect to the book, there were too many ideas per page. Instead, I split up each page by single idea. In this way, I could illustrate individual thoughts and experiences for struggling readers to match with the text and audio.

The book itself continued to grow and grow. I began writing and illustrating a set number of pages. However, when I laid out the initial design with illustrations and text, I could more easily see the holes. I saw that I wanted more than one prominent character. Knowing that dyslexia is an umbrella term for multiple types of learning disorders, I saw the need for characters that could explain a range of dyslexic symptoms and mirror a broader range of experiences. While Anna remains the protagonist and primary narrator, her brother, Sam, and best friend, Julia, provide mini-narratives of their own.
Conclusion & Reflection

This project was, at its core, driven by personal experience. Reflecting on my experiences in school, I discovered that as a child I lacked an understanding of myself as a student in an academically focused world. I noticed that I could remember the traumatic side of being diagnosed with learning disabilities, but no memories of the relief or discovery of how I really learn and how I am not alone. I needed some sort of guide.

While I focused on creating a guide to self-advocacy and demystification for kids, I did so for myself as well in the process. Throughout this project, I researched and answered my own questions, stemming from those I had as a child to those I have as a teacher and adult. In doing so, I began to fill in the blanks that lingered into my twenties. I reflected and discovered more about the way in which I learn and process information.

As I produced more and more pages for young readers like myself, I also began to find the words to advocate for myself. As I dug into research about experiences with dyslexia, I felt like I was reading about myself. Each page I turned, out sprang an “aha!” moment. It turned into a therapy of sorts and a process of self-acceptance. I began describing my project to everyone I encountered and I became increasingly comfortable telling people the impetus for the project: my own dyslexia. Slowly, with each person I told, I felt more empowered. I began breaking down my project and my disability into a powerful elevator pitch: I am writing a book about dyslexia for kids with dyslexia to teach them about themselves. It is something I wish I had as a child with dyslexia.

I noticed something happen as the number of friends and family I told about my project. While I once felt like the only person in my world to have trouble reading and writing, suddenly
I was not alone. Those who I always admired for their intelligence and academic ability started to come out as dyslexic. Friends I had worked next to in the college library for years suddenly discussed their diagnoses. Their partners, upon hearing their responses, would reveal that they too were diagnosed with learning disabilities. The more I talked about my project, the more people came forward with an identity that seemed to be bottled up. They began to tell me their experiences and share their own fear of the taboo. One friend seemed relieved, “I always wondered why we were both spending so much time on our work.” This phenomenon finally culminated in my own brother’s response. Just one month after graduating from Harvard Medical School, he confessed his own learning difficulty. “I switch around the first and last letters of words,” he told me on July 4th as we worked side-by-side at a coffee shop. “I have always read slower than others. In college, I realized I would need to choose one: reading or friends.” Never officially diagnosed, he had developed a work ethic that not only allowed him to succeed, but surpass expectations. He also found ways to hide the need for additional support.

By finally talking about dyslexia in a confident manner, I was also normalizing it. In each of these moments of realization and confession, noticed that I not only began to feel a special bond with those around me, but there seemed to be a sigh of relief. For the first time in my life, dyslexia no longer seemed like something to mark “CONFIDENTIAL.” Instead, it became a source of mutual respect.

At the beginning of Melvin Levine’s book *A Mind at a Time* (2002), he writes:

“Planet earth is inhabited by all kinds of people who have all kinds of minds. The brain of each human is unique. Some minds are wired to create symphonies and sonnets, while others are fitted out to build bridges, highways, and computers… The growth of our
society and the progress of the world are dependent on our commitment to fostering in our children, and among ourselves, the coexistence and mutual respect of these many different kinds of minds” (p. 13).

We need to begin to rethink the way to value and approach differences in learning and processing. The more people I encountered with dyslexia, the more I realized that our learning system relies too heavily on the idea of a typical brain. Everyone I talked to seemed to feel like they had “beat the system.” They managed to make it through graduate programs to become photographers, art historians, doctors, and lawyers. They thrived in their careers after complying with a system of specific expectations.
References


living-with-dyslexia/school


dyslexiahelp.umich.edu/dyslexics/living-with-dyslexia/self-advocate-for-your-dyslexia


Dyslexia? A Kids Only Guide To Understanding Dyslexia

Written & Illustrated by Anna Slavin
This book is dedicated to my students, my mentors, my friends, and my family. As a kid, you patiently led me to understand how I learn best. As an adult, you patiently showed me how to help others do the same.
Hi! My name is Anna.

When I was a kid I learned that I have dyslexia. I learned ways to help myself learn to read and write. Now, I am a teacher and help kids figure out how they learn best.

This is a KIDS ONLY book I wrote based on my life as a kid with dyslexia.

You can read it or listen to it WITHOUT AN ADULT (but don’t be afraid to ask for help).

I love to draw and paint so I made some pictures to help you see what I am talking about.
Learning in school is hard for me when I have to read or write.
The letters jump around on the page, it is hard to remember the sounds letters make, and occasionally letters just disappear.
When I have to read in class, I sometimes feel embarrassed. I know that how I see words and how I read is different than my friends. It can make me feel sad and scared to do work around my classmates.
What if they tease me?
Sometimes I think my brain is playing tricks on me.
It isn’t!

My brain is different. It is called **dyslexia** *(dis–lek–see–uh).*

I see letters and words differently.
Dyslexic kids CAN read.
But... Dyslexia is called a learning disability because we learn to read, write and look at numbers in ways that are not usually taught in school.
There are lots of kids with dyslexia, but no two kids are the same. I had trouble reading words because letters jump around on the page. Some students skip words and letters while reading. Others have a hard time remembering words. Other students with dyslexia might run into trouble when trying to learn new words.
My brother Sam also has dyslexia. Unlike me, Sam read and wrote words backwards when he was a kid.
Dyslexia can also make math difficult!
Math is hard for my best friend, Julia. It is hard for her brain to keep the numbers organized on paper. There is a special word for dyslexia in math:

**Dyscalculia**

(dis-cal-coo-lee-ah)
Don’t be fooled by the name "learning disability." Kids with learning disabilities are just as smart as kids without them. Everyone thinks and learns in a different way.

Dyslexia, like other types of learning disabilities, is a way of describing a specific way of thinking that is not as common in our schools.
Does dyslexia make thinking hard?

Kids with dyslexia have minds that think in amazing ways that “typical brains” can’t. Reading may be hard, but thinking isn’t!
Brains are the control center of our bodies.
Different parts of the brain control what we do every day, such as breathing, speaking, hearing, and seeing.

Brains use neurons to send messages to other parts of the brain and throughout the body.
The cerebral cortex (say it out loud: seh-ree-brel-kor-teks) is the outer layer of our brain and is one of the parts of the brain responsible for skills like thinking, learning language and solving problems.
No two people are the same and every human brain is different. Scientists use a model of a “typical” brain to learn how brains can be special and unique.

Dyslexic brains are mostly different from “typical” brains because of how the cerebral cortex sends messages. When we read and write, our brains work harder to organize written language.
My brain gets tired when I read and write.

What about you?

Let's see how similar we are. Next to each statement, there is a dotted line T and a dotted line F. Trace the T if the statement is true for you. Trace the F if the statement is false.
I read slowly and get frustrated if I do not have time to finish.

I prefer to only read for short periods of time. Reading makes me tired easily.

Letters can be confusing and I often mix up letter or number pairs such as b/d, p/q, h/n, 6/9.

I mix up my upper and lower case letters.

I often miss letters and words when reading and writing.

Sometimes I read words without any trouble but don’t remember what I read or what it means.

My work often looks messy. I erase a lot.
If you look at a picture of yourself and someone in your biological family, you might notice some things that look similar. Maybe you have the same hair as your mom and the same eyes as your dad. You inherited those features from your parents.
Scientists believe that dyslexia is inherited from your family.

This is my mom. She is also dyslexic.

This is me. I inherited dyslexia, brown eyes and rosy cheeks from my mom.
People cannot agree on the exact number of people with dyslexia.

It could be anywhere between 5 to 10% of students in the United States of America.
That means...
...if you have 100 kids in your school only between five or ten kids will have dyslexia. If you have 10 kids in your class, you might be the dyslexic student.
That means our minds are unique but we are also not alone.
Even though having a dyslexic brain is awesome, it also still means that you will often need to work harder than your friends to learn to read.

You may feel more frustrated.

You may need to ask for more help with school assignments.

You may need some special tools and tricks to help you with written work.

You may need to go to special classes in a resource room or with a tutor.
If you learn about your dyslexia, you will find better ways to learn to read and write. You can now become your own superhero.

When reading feels hard, you can use new tools to help yourself or ask others for help.
If you had a friend who was born with a knee problem, a doctor would do some tests and discover what made it difficult for your friend to run.

Then, they would visit the doctor every week to learn exercises to become stronger.
Instead of your knee, it is your brain. You think differently. Tutors and teachers can help you strengthen your brain to become a better reader. They will give you brain exercises and tools to help you when reading, writing, and learning feels hard.
My friends and classmates are always asking me questions.
Why do you leave the classroom for special lessons?

Why does the teacher give you extra time to read?

What is a learning disability?
You now have the information to answer all of your friends’ questions and to decide how you will use your dyslexic brain.
Tell your friends what is hard and what is easy for you in school.

Explain your learning plan clearly so friends can understand the difference between “not able to learn” and “learn differently.”

Let your friends know your strengths and teach your friends about how the brain works!

**REMEMBER**
You never need to share your dyslexia. It is your choice how you want to talk about how you learn!
Dyslexia is a way of thinking and learning. Some of the world’s most important thinkers, such as Albert Einstein and President George Washington had dyslexia.

Even though school may have been hard, their creativity and new ways of thinking changed the world!
Draw a picture of yourself doing what you are proud of:
For you & an adult:

The average school (public or private) is not designed for students with dyslexia. Be an advocate for your child and encourage self-advocacy as well. Finding the best available services and resources for your child with dyslexia can make a world of difference in their confidence and ability to do well in school.

Informing your child about their dyslexia and tools that will help them with is very important. Studies prove that students who can define themselves with dyslexia can also independently help themselves more in school and do better both socially and academically.
For you & an adult:

Multi-sensory Structure Language (MSL) reading programs are known to be the most effective and fun. Orton-Gillingham based program are the most widely accepted as effective.
There are many stories based on students with learning disabilities and a growing collection of stories that identify students with dyslexia. Here are a few of my favorites:

The Alphabet War: A story about dyslexia by Diane Robb

Thank You, Mr. Falker by Patricia Polacco

Close to Famous by Joan Bauer

What is Dyslexia?: A Book Explaining Dyslexia for Kids and Adults to Use Together by Alan M. Hultquist

It’s Called Dyslexia by Jennifer Moore-Mallinos