**NSCI 483: Advocacy Plan (ADHD)**

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**Review: Attention Deficit Hyperactivity Disorder (ADHD)**

**History**

The notion of inattention as a disease was introduced in 1798 by Sir Alexander Crichton, who described, in the second chapter of *On Attention and its Diseases*, that a person “could suffer the incapacity of attending to any one object with a necessary degree of constancy”, and that he could be “incessantly withdrawn from one impression to another” (Crichton, 1798). This disease afflicted children and diminished with age. In 1902, Sir George Frederic Still observed 20 children (15 boys and 5 girls) and spoke of a “defect of moral control”, in which they seemed to be unable to resist self-gratification, even if the consequences were negative (Still, 1902).

This defect was not understood to have a biological basis until 1937, when Charles Bradley reported that stimulant medications showed positive results for treating children with behavioural disorders: in a systematic trial for the use of benzedrine, he observed that half of the children showed drastic improvement in school performance and motivation (Bradley, 1937). In 1944, the Ciba-Geigy company produced methylphenidate, marketed as “Ritalin”, the drug of choice in treating ADHD even to this day (Lange et al., 2010).

This condition, termed by the Oxford International Study Group of Child Neurology as “minimal brain dysfunction” was eventually recognized to have three clusters of symptoms: inattention, impulsivity, and hyperactivity. It was later reclassified as “hyperkinetic reaction of child” in the DSM-II (Diagnostic And Statistical Manual of Mental Disorders, Second Edition), before becoming “attention deficit disorder (with or without hyperactivity)” in the DSM-III (Third Edition). Today, it is known as attention deficit hyperactivity disorder (ADHD), and the diagnostic criteria accommodates greater knowledge on the disease. We recognize that ADHD can persist or develop into adulthood. Furthermore, we recognize different manifestations of ADHD and diagnose according to subtype. Finally, we recognize a multifactorial etiology, with genetic, neurobiological, and environmental factors (Lange et al., 2010).

**Behavioural Manifestations, Diagnostic Criteria**

Within the DSM-5 (2013), ADHD is characterized as a neurodevelopmental disorder usually diagnosed in infancy, childhood, or adolescence. There are three subtypes: predominantly inattentive; predominantly hyperactive-impulsive; or combined type. The patient must demonstrate six or more of the listed symptoms, persisting for at least 6 months, to a degree that is maladaptive and inconsistent with their developmental stage. Inattention refers to symptoms like failing to follow instructions, poor listening and attentiveness, and disorganization. Hyperactivity-impulsivity refers to symptoms like excessive restlessness or speaking/acting out at inappropriate times, which interferes with social/academic functioning. Along with subtype, the clinician can specify if the disorder is in partial remission, and if it is mild, moderate, or severe (American Psychological Association, 2013).

ADHD is typically discussed within the context of education, but the disorder has severe consequences in other domains. People with ADHD are susceptible to psychosocial risks, such as substance use and unprotected sex (Sarver et al., 2014). They are less able to regulate their emotions and may respond inappropriately to strong emotions (Bunford et al., 2014). Even more, ADHD can create elevated risks of mental health issues, such as depression and suicide ideation, in both children and adults (Trivedi et al., 2023; Fenesy & Lee, 2022; Solberg et al., 2017).

It is important to note that sex differences influence the behavioural manifestations and consequences of ADHD. Generally, men have higher rates of ADHD diagnosis: in Ontario, the prevalence of ADHD among young people (ages 1-24) is 7.9% in males, and 2.7% in females (Hauck et al., 2017). However, this imbalance may reflect that males tend to have ‘externalizing’ symptoms that are more easily detected (i.e., impulsivity), while females tend to have less visible symptoms (i.e., inattention) (Mowlem et al., 2018). One additional note is that they are at risk of different psychiatric comorbidities: Men with ADHD showed greater prevalence of comorbid schizophrenia and substance abuse, whereas women with ADHD showed greater prevalence of comorbid anxiety, mood, and personality disorders (Solberg et al., 2017).

**Etiology and Pathophysiology**

ADHD is highly heritable in families, and it has higher heritability than most other psychiatric conditions. Evidence comes from sibling studies, in which identical twins (who share 100% of their DNA) were found to be at much greater risk of having ADHD if their sibling had ADHD, compared to regular siblings (who share 50% of their DNA), half-siblings, and cousins (Chen et al., 2017). This knowledge has prompted investigation into ADHD susceptibility genes: for instance, Šerý et al. (2015) found that variants in the DAT1/SLC6A3 gene, which is involved in dopamine regulation, were associated with ADHD. Nevertheless, not all the risk can be explained by genetic factors; both physical factors (ex. maternal smoking during pregnancy) and psychosocial factors (ex. family dysfunction) can predispose a child to the development of ADHD (Huang et al., 2018; Russell et al., 2015). In popular culture, there is the idea that increased use of technology and social media can contribute to the development of ADHD. Although Farchakh et al. (2022) confirm that higher problematic social media use was associated with higher odds of having ADHD, it is unknown whether social media use causes ADHD, or whether ADHD causes greater use of social media.

At the neurobiological level, ADHD is hypothesized to involve dysregulated frontostriatal circuits, which are regions of the brain involved in reward processing, emotional regulation, motivation, and inhibition. Evidence comes from Munoz et al. (2003), who discovered that patients with ADHD are less capable of suppressing unwanted eye movements (saccades) and controlling their fixation behaviour, a symptom of frontostriatal dysfunction.

**Current and Emerging Treatments**

ADHD treatment begins with psychoeducation. This approach involves improving patient’s understanding of the disorder, so that they gain insight on how they can improve everyday functioning. After, treatment typically involves a combination of pharmacotherapy (medication) and psychotherapy to help promote positive behaviour patterns. Physicians start at the lowest possible dose and prescribe long-acting stimulants, such as methylphenidate or lisdexamfetamine, as first-line treatment; these treatments can be augmented or replaced by short-acting psychostimulants, or with non-stimulant norepinephrine reuptake inhibitors. Psychotherapy (in either individual or group settings) aims to help patients alter maladaptive habits and to address potential problems with self-esteem, confidence, and interpersonal relationships.

Since stimulant use is accompanied by adverse effects (i.e., cardiovascular events), researchers are investigating therapeutic alternatives. One emerging option is trigeminal nerve stimulation (TNS), a form of noninvasive neuromodulation: the trigeminal nerve is mildly stimulated as the patient sleeps to activate frontal regions involved in ADHD. Although more research is needed, TNS was shown to significantly improve symptoms of ADHD, without major adverse effects (McGough et al., 2019). As knowledge on the connection between eye saccades and ADHD grows, researchers are investigating the use of eye-tracking technologies as a noninvasive screening tool, which would allow patients to receive treatment and accommodations earlier in their life (Yoo et al., 2024).

**Advocacy Plan**

**Challenges**

GL experiences a predominantly inattentive form of ADHD. She reported a lack of focus or motivation to complete schoolwork, and therefore an inability to progress towards long-term goals. She also faces difficulty with listening and following a conversation, which has previously led to social consequences. Finally, she becomes sidetracked by external, unimportant stimuli.

There were three major barriers in her story. The first barrier was her difficulty in accessing timely care: she described everything going smoothly one she received her diagnosis, but that access to a psychiatrist was the limiting factor. Since the entire healthcare system buckled under the strain of COVID-19, GL’s difficulty in accessing care was not a specific indictment on ADHD care. However, it does show that when it comes time to prioritize, mental health challenges are often pushed back; and although this is understandable in emergency situations, these challenges build in magnitude, eventually reaching a breaking point. The second barrier was stigma and lack of awareness surrounding her diagnosis. As a functional adult who did not fit the stereotyped ‘image’ of ADHD, it was difficult for GL to recognize her symptoms until a friend recounted his own experience. After this, she struggled with stigma, both from herself and her family. Her family members expressed doubt that she had ADHD, so GL had to advocate for herself; but even she wondered (and still wonders) if she was “making her disorder up for attention”, and if she was “gaslighting” everyone around her into confirming her diagnosis. The third barrier was in navigating academic life following her diagnosis. As GL prepared to take the MCAT (Medical College Admissions Test), she sought accommodations; however, the process to apply was so expensive and convoluted that it would be more difficult to receive accommodations, than to take the test as it was. So even after diagnosis, GL needed to “prove” that she was really ADHD.

In many parts of her story, GL is fortunate. She had access to a family physician, and it was a happy coincidence that he had expertise in ADHD. Once she received her diagnosis, she was able to access treatment in a timely manner, as medications/counselling were covered under her student insurance. And as a young person with generally good health, GL can use the medications, despite side effects. GL expressed gratitude as she reflected on this; but she also recognized that what was easy for her is difficult for individuals who come from different circumstances. Without her family doctor or university health system, she could not have obtained a referral. Without her university insurance, she would not be able to afford medications, as the monthly costs accumulate to a significant degree. Without her health, she would have to discontinue her medication use if the side effects were too grave, or she would have to undergo a lengthy process of testing drugs until finding one that worked.

After reflecting on her experiences, I propose three ways in which we could support and integrate another person like GL: by detecting ADHD beyond the stereotype; by providing help in navigating the healthcare system; and by respecting individuals with ADHD not only as people with disability, but as people with diversity that could strengthen society.

**A. Detecting Beyond the Stereotype**

The stereotypical image of ADHD is that of a young boy who cannot sit still: he disrupts the class, fidgets, does not study, and then does poorly on the test. It is harder to see ADHD in a straight-A student, who takes her exams with great care and composure. Perhaps this student compensates for her inattention in class with frantic late-night cram sessions at home, but as long as her results look good, her dysfunctional process will go unnoticed by herself and others. GL was high functioning throughout school, and it was only once she could not sustain her success did she recognize that her habits were disordered. In GL’s case, she received her diagnosis in early adulthood and has been managing her symptoms well. Unfortunately, many cases of adult diagnoses involve a profound sense of loss (Goldbloom & Davine, 2019), because if they had known earlier in life, they could have avoided years of unexplainable chaos, or of underachievement falsely attributed to laziness or stupidity. If they received treatment, they may have been better able to defend themselves against issues (ex. substance abuse) that arose as consequences of undiagnosed symptoms.

This is a significant gap in the system that would benefit from early intervention. To promote positive development, I believe that we must look beyond the traditional view of the rambunctious schoolboy as ADHD, and the quiet schoolgirl as totally fine. I advocate for standardized screening for ADHD across Ontario schools: once children reach a certain milestone (ex. Grade 3), a screening tool is sent out to families, and students who show signs of ADHD on the screening are directed to a psychologist. The psychologist can further assess the child, keeping in mind the diversity of ADHD presentations, and either direct them to seek medical help (if the child likely has ADHD) or provide them with information on how to improve warning signs (if the child likely does not have ADHD). It is feasible to administer screening on a wide scale because it is already done in other capacities. For example, Ontario administers an assessment in Grade 3 children to determine if they are gifted, so that they can be put in another stream of education; Ontario also administers the standardized EQAO test for literacy and numeracy. Academic evaluations are important, but they are not fully indicative of a child’s healthy development. If screening for ADHD can be administered as an add-on to the gifted test, or even as another milestone evaluation in a child’s schooling, then we could detect ADHD in children with “high functioning” or other atypical manifestations.

It is still possible for some children to be missed, or for ADHD to develop in adulthood. To detect ADHD in adults, it is important to share stories and education about ADHD in workplaces and communities, in case they strike a chord within an undiagnosed person. It is also important to create spaces, ideally within the workplace but also outside of it (and virtually), in which people can safely seek help for their mental health concerns. Discussions about mental health frequently involve judgment, both from oneself and from others. Some people fear appearing weak; some people fear ostracization from their communities; and in GL’s case, she fears that her ADHD was imagined in her mind. Even if an adult is not diagnosed for ADHD, it is important that they feel safe to explore the possibility and receive help for any challenges.

**B. Navigating The Healthcare Nebula**

When seeking a diagnosis, GL intended to go through the traditional route of consulting her family physician, receiving a referral to a psychiatrist, and being diagnosed by the psychiatrist. Unfortunately, it would take months to be seen by a psychiatrist. Therefore, GL switched gears and sought help from her university’s clinic, with doctors who could see her a little earlier. Although it was hard to navigate the system, GL considers herself lucky because she had a family doctor with ADHD expertise, and she had health insurance with her university. It also helps that GL was studying biology, so she and her peers were more educated than most on mental health disorders. Both of us wondered: how would someone with less of a health background and less material resources begin to navigate the system?

The Centre for ADHD Awareness Canada (CADDAC) is a non-profit organization that provides education and resources for ADHD, across all age groups, genders, and subtypes. Along with their general guides, they have a designated “ADHD Resource Navigator” to help patients and families navigate the system in their communities, and to build their self-advocacy skills. I propose that this role would be good to implement on a larger scale, not just in ADHD advocacy communities but also in schools and workplaces. With the growing use of generative AI, we could develop ‘virtual’ navigators, who help patients to strategize the most effective way to overcome hurdles in the system: accessing a doctor, paying for treatment, or applying for accommodations. Because there is so much ambiguity around the process, having an experienced guide can help patients feel less overwhelmed and more empowered to self-advocate.

**C. Neurodiversity Can Be Bad, But It Can Also Be Good**

It never occurred to me that people could see ADHD as a positive ability until my interview with GL, when she mentioned some cool features of her cognition. I had only once read an article that proposed that, in primitive societies, ADHD was an adaptive trait. For example, the ability to notice and to be distracted by external stimuli might have allowed the ADHD hunter-gatherer to detect and escape from incoming threats sooner. In fact, a recent study by Barack et al. (2024) investigated this hypothesis by asking participants (while screening for ADHD) to complete an online foraging task: they found that those with ADHD symptoms performed better and received greater rewards. This hypothesis suggests that ADHD comes from environmental mismatch. In school environments where children are rewarded for quietness, and in work environments where adults complete sedentary and repetitive tasks, those with ADHD struggle to succeed. This causes many patients with ADHD – who could be so quick and creative in a different setting – to lose their sense of self-efficacy and to never realize their capabilities.

Therefore, I propose that alongside discussions of ADHD and accommodations, we should emphasize that individuals with ADHD have cognitive strengths that can be actualized in the right environment. I don’t mean to say that ADHD is a “superpower”, and that all patients have the same cognitive strengths; I mean to say that ADHD should not be viewed just as a weakness, but as neurodiversity that could be an asset. For example, someone with an impulsive nature may thrive in turbulent types of work, but he will never realize it if confined to a desk. If therapists, teachers, and clinicians are trained to enlighten patients on their ability alongside their disability, they may have greater self-knowledge to seek environments that successfully ‘match’ their disposition.

The last change that I propose is to view patients with ADHD as the experts on their own disorder, and to elevate them to leadership positions to effect change, by promoting equitable accommodations in schools and workplaces. When GL recounted her frustration with MCAT accommodations, I realized that this barrier actively blocks students with ADHD from entering medical school. Even worse, these are the people that we desperately need in medicine because GL mentioned that she benefited enormously from having a doctor with expertise in ADHD. Doctors with ADHD may have more empathy for their patients with ADHD; and because of their lived experience, they could be researchers, policymakers, and advocates who create significant improvements for society, by ameliorating the negative impact of ADHD in their communities. All these advantages are lost if we fail to provide accommodations that allow patients with ADHD to succeed.

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**Interview Summary**

<p>To start, I asked GL to describe when she suspected something was wrong, and how she received a diagnosis of ADHD. As a child, GL never thought that she had ADHD because she was high functioning: she had good grades in school and no behavioural issues, and she did not struggle with friendships and relationships. She began to struggle when she entered university in 2019, as she could not pay attention, focus, or motivate herself to study. She would only study for exams until the deadline was a couple hours or days away; it was only once stress (or “high-strung excitement from a random niche interest”) kicked in that she could begin to do work. GL described an “all-or-nothing” response, in which she could only work when she was hyperfixated on the topic. In her social life, her interactions suffered; as she spoke to others, she was easily distracted and could not focus on the person in front of her. In retrospect, GL had always experienced these symptoms; but they were unmanageable in 2020, especially as the university shifted format to accommodate COVID-19 restrictions. She did not realize that her experiences could be symptoms of ADHD until one of her close friends was diagnosed with ADHD in her second year. As he recounted his symptoms, GL felt like she related deeply. Because one anecdote wasn’t enough, GL did her own research and looked for others’ stories. With more questions, she looked for a physician who could help her find answers. </p>

<p>The process was not as straightforward as she had hoped. During the pandemic, doctors were overburdened by more urgent concerns. GL agreed that naturally, someone with a heart attack should be prioritized over someone with non-emergent ADHD… but at the same time, her needs were being delayed, and her mental health was placed on the backburner as her grades and energy suffered. In third year, her friends advised her that university doctors were more accessible. The waitlist for a psychiatrist was 2 months, rather than 6 months (with a referral from her regular family doctor) … which was not optimal, but workable. While waiting to see the psychiatrist, GL spoke to her family physician, who had a background in children with ADHD. He spoke with GL about her symptoms and screened for other conditions, such as depression or anxiety. GL felt lucky to have a family doctor with an ADHD background, as he felt comfortable prescribing her with medication to use in the interim (but GL noted this does not usually happen). GL met with the university psychiatrist for a 1–2-hour appointment, in which GL was asked to produce prior report cards, teacher’s comments, and statements from loved ones about her symptoms. Through extensive discussion, the psychiatrist ruled out other psychiatric challenges, before diagnosing GL with ADHD. </p>

<p>I asked GL to reflect on the process of receiving a diagnosis. Many of her barriers to accessing healthcare were natural consequences of the pandemic, but GL also mentioned barriers due to stereotypes associated with ADHD. When we imagine someone with ADHD, we imagine a hyperactive child “bouncing off the walls”, who is unable to sit still school. However, GL’s ADHD corresponds more with the “attention-deficit” part of ADHD, in which she lacked focus and motivation. Furthermore, GL did well in school and seemed fine; therefore, her symptoms were “masked”. Because she was not the stereotypical picture of ADHD, no one in her life – not even GL herself – detected the disorder until adulthood. </p>

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<p>Since her diagnosis, GL has been using stimulant medication to manage her symptoms. She has found the treatment to be effective, observing large improvements in her academic and social life. For one, GL feels like she is “actually learning”, because getting everyday tasks done (like booking an appointment or following through on plans) no longer feels so burdensome. She has more executive control, allowing her to decide when and how to study. In addition to medication, GL also consulted an academic counsellor, but she felt that she did not need this. She already knew about the study strategies the counsellor recommended – the hard part was to actually apply them, which the medication helped her to do. </p>

<p>Nevertheless, GL mentioned difficulties with the stimulants. Initially, she was so excited by the ability to focus that she went “too hard” with her studies, leading to burnout – but she has since learned to prioritize work-life balance. There are also side effects. She must take it at the right time, or else she would be unable to sleep at night. Since her medication suppresses appetite, she has struggled with eating enough food to get through the day. She has a nagging concern for her cardiovascular health, as the medication increases heart rate and blood pressure. </p>

<p>GL has used academic accommodations: her school has offered extra time for tests and assignments, as well as separate rooms for completing exams. She has found them to be helpful, as she found writing an exam in a room with 600 other students to be incredibly distracting. Extra time helps GL complete her assignments with more diligence, and her grades have improved with these changes. If she could propose another accommodation, it would be to reintroduce paper exams, as she struggles to focus with computer tests. Her university has been generally accommodating, but GL experienced significant difficulties when she sought accommodations for the MCAT (Medical Colleges Admissions Test). Despite having two diagnoses from two physicians, she reported that the AAMC (the administering body for the MCAT) required applicants to undergo a $5000 psychiatric evaluation that was “ridiculously niche and specialized”. Since the MCAT is such an important test, of course some students would want to gain an advantage by inappropriately using accommodations; but the cost and effort for one’s diagnosis to be validated by the AAMC poses huge barriers to students who need it the most. Consequently, GL wrote the MCAT without accommodations and found her test conditions to be extremely distracting. Really, a quiet, separate room should not have costed $5000 to obtain. </p>

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<p>Next, I asked GL about her experiences with stigma and misconceptions of ADHD. Many people have made off-hand, dismissive comments about her ADHD: for example, making jokes about being so “ADHD” to describe someone being a little more energetic than normal, or remarking that “everyone has ADHD these days”. As someone with “high-functioning” ADHD, GL faced pushback from her parents, who did not believe she had ADHD but eventually supported her decision to consult a doctor. When she started treatment, GL’s parents attributed any moodiness or irritability as the fault of her medications, which frustrated GL for their inability to understand her disorder. But nowadays, GL feels very supported: her family and friends do not care that she has ADHD, only that she is doing well. She is grateful for this; but the final source of stigma comes from herself, in which GL wondered (and still wonders) if she had “made up” her diagnosis, if she had confused it with burnout, or if she had somehow “gaslit” her doctors and families to support her ADHD as an unconscious bid to seek attention or to seem “special”. </p>

<p>I asked her a question about if ADHD has grown in incidence not because of natural causes, but because of a modern environment, in which people are overstimulated by work and technology. She noted that environment is implicated in the development of any disease, and that many emerging fields (like epigenetics) are dedicated to unraveling the influence of nature vs. nurture. But even if her ADHD is artificially produced, she must find a way to live within this environment and to seek help for her dysfunction. GL made an analogy to a cancer patient who lives near a nuclear reactor: the unnatural environment was the cause, but the cancer is very much real. Treatment should involve medication, but also moving away from the reactor; similarly, ADHD treatment should involve medication and cognitive strategies to improve executive function. </p>

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<p>To conclude, I asked GL what she hoped to see in the future, as well as any insight not covered by my previous questions. She advocated for people to have a better understanding of ADHD, in which small things (like requests to slow down in conversations) are gently respected. It’s a hard problem to solve, but more physicians with ADHD expertise would streamline the process of diagnosis. She is not too familiar with ADHD research but hopes for continued work to understand the etiology, as well as treatments that have less side effects. </p>

<p>As for special insight, she mentioned that, although her ADHD causes problems in her life, it does have its perks. She mentioned sometimes achieving a ‘golden zone’ for stress, where she feels mentally clear and finishes things extremely quickly. On the medications, her head is an echo chamber; but off, her head is a series of trains crashing one after another – which isn’t pleasant, but the cool thing is that she can jump between trains of thought extremely quickly and figure out different paths. When I brought up a theory that the distractibility of ADHD might have had evolutionary advantages in a primitive society, she mentioned her ability to quickly pick up small details in her surroundings, leading people to think that she had excellent memory. But in reality, she feels an inability to prioritize; everything is a priority, so even insignificant things are noticed. </p>

I have been long-time friends with GL, despite only seeing each other once every half-year. She is one year older than me, so she went off to university as I was finishing high school. Then I went to a university in the opposite direction. Very rarely are we ever in our hometown at the same time. Nevertheless, we have stayed connected over the last 6 years, supporting each other when we experienced our greatest victories, or in our most magnified crises.

A lesson in unlearning prejudice. …

Months of our university experiences were subjugated by COVID-19, and both of us witnessed its nuclear consequences: the total abandon of scholarly integrity and motivation, the inadequacy of Zoom University in producing meaningful social connections, the whiplash-inducing disruptions to our living situations. But even if coronavirus did not happen, it is a feature of every student’s experience that they push off their nightly assignment to watch one more TikTok, then show up to class sleep-deprived the next day; that they sometimes submit things at 11:59 P.M. or miss the deadline entirely; that they will not feel motivated in every single class they take. Certainly, students need help if they struggle to succeed in school. But what is the line between normal and abnormal dysfunction, especially for something as fickle as attention? I trusted that my friend knew best what she needed to do – but I did have reservations.

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At the end of the interview, I asked GL if there was anything I failed to ask about in my questions, if I had missed any insight or aspect of her disability. Turns out that I had missed the ‘ability’ part of her ADHD.

I was first introduced to the concept of neurodiversity in a book called “Far From the Tree” by Andrew Solomon, and I know that this term has re-emerged in the Generation Z zeitgeist, as more of us become aware of mental illness topics. Just like we benefit from having people of different cultures…. Is it not beneficial in a society to have a subset of people who can hyperfixate on their topics of interest, whose interests flexibly shift at the drop of the hat, who are good at detecting minute changes in the environment? I imagine there is danger in aggrandizing neurodiversity – we never want to imply that ADHD or any other divergence offers immutable advantages in creativity, spontaneity, and general coolness over those *neurotypical commoners*. However, many people with neurological disorders struggle in society because they do not know how they can meaningfully participate, when it demands sedentary deep focus in its most powerful occupations. Perhaps some encouragement and self-knowledge would help them find their way into vocations that play to their strengths the most.

Upon finishing my report, I sent it to GL. “Let me know what you think!”

“It’s actually really cool to read my thoughts like this because it’s organized now. I struggle to synthesize everything coherently, so it’s nice to be able to hear myself now that everything’s been organized.”