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Ethical Concerns Raised by Neuroscience, Labeling, and Intervening in the Lives of Individuals with ADHD

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1. Introduction

Take a moment to consider how individuals with Attention Deficit Hyperactivity Disorder (ADHD) are described. When people talked about these individuals what do they say about their behaviors, bodies, and minds? Do these descriptions vary across individuals, contexts, and time? Now compare your reflections as to how individuals with ADHD are often described. In today's world ADHD is described as a:

- disorder/dysfunction.
- heterogeneous developmental disorder.
- chronic condition with life-span implications.
- brain difference.
- delay or deterioration in their cognitive, social, and emotional functioning.
- universal condition transcending culture, socio-economic, and race.
- social and emotional burden.

These descriptions are common and, as a matter of fact, most of them were drawn from chapters in this book.

My point for using this activity to open this chapter is to make you aware of your personal theories and how the symptoms of ADHD, who has it, and what happens as a result is influenced by our perspectives. Let me clarify what I mean a bit more with a boy name Michael and a role-play for you. Imagine that you are a teacher and Michael is a student in your classroom. You enjoy Michael's humor but he is showing uneven academic progress and is

constantly fidgety and out of his seat. Take a few minutes to answer these questions: From where is Michael's lack of progress stemming? Why is he so fidgety and out of his seat? What would you do to help Michael?

Now, let's consider some common answers. If you thought Michael's uneven progress and fidgetiness stemmed from his family's lack of discipline you would likely direct Michael and his family to a counselor, who in turn might place them in some sort of counseling or therapy. If you thought Michael's uneven progress and fidgetiness came from a brain difference you would likely refer Michael to the school psychologist, who in turn might refer him to a physician, who might place Michael on medication. If you thought Michael's uneven progress and fidgetiness stemmed from his environment (your classroom) you might decide to differentiate his instruction and restructure the activities he was given so he could get up and move. Three varied perspectives of Michael with three different outcomes. No perspective was neutral and each set Michael on a different path.

To take the idea of teachers' perspectives about boys like Michael one step further let me explain a study conducted by two colleagues and myself (Zambo, Zambo & Sidlik) in 2009. We wanted to understand what teachers thought about individuals with ADHD and if neuroscience was useful to them so we based on the work of McCabe and Castel (2008) and Weisberg, Keil, Goodstein, Rawson, and Gray (2008). These researchers manipulated information and used an fMRI image, a graph, or no image to understand if neuroscience was persuasive and they found it was both persuasive and misleading. These researchers concluded that fMRI images were persuasive because they appealed to their participants' intuitive reductionist notions of learning and confirmed theories and biases they already possessed (learning boils down to brightly lit areas captured in fMRIs). Instead of thinking of learning as a complex process unable to be reduced to biological functions alone, participants believed colorful images proved learning had occurred.

Based on this work, we set out to understand what a group of preservice teachers knew about ADHD, where they learned this information, and what they thought about medical science and neuroscience being useful to them to educate students with attention challenges. We used a general questionnaire but manipulated the type of information participants received. Half of our participants saw an fMRI image and read about ADHD from a neuroscience perspective (e.g., caused by faulty neuroreceptors responding to the neurotransmitter dopamine) and the other half saw an image of a premature infant and read about ADHD from a medical perspective (e.g., infants being born prematurely and weighing less than 3.3 pounds often develop ADHD).

We found that the participants in both groups knew a lot about the behaviors of students with ADHD. They knew, or at had theories that, students with ADHD were hyperactive, excitable, impulsive, irritable, and seldom tired. They also believed that these characteristics inhibit students' learning and social life. They believed that children with attention challenges were distractible, struggle with concentration, get off task easily, and have social and family problems. When asked where they learned this information they said they had friends or family members with it, heard celebrities on television talk about it, and discussed it in their courses (especially special education courses).

Data from the two conditions (neuroscience and medical science) showed some differences. Participants who saw the fMRI image and read information suggesting ADHD was a biological disorder believed that neuroscience would be useful to them. These participants believed information from neuroscience would help them identify students with ADHD, understand how their brain works, and understand why they behave in certain ways. Participants in the neuroscience condition also thought neuroscience would help them teach these students. They thought neuroscience would show them how to create learning environments and lessons conducive to these students' needs.

In comparison, participants in the medical science condition, who saw the image of the premature infant and read information from medical science also saw it as useful but had different theories about its use. Participants in this group thought medical science would help them understand the cause, signs, and symptoms of ADHD, the importance of medication, and how to manage students' behaviors. Different conditions lead to different perspectives of students with ADHD.

I hope these results help you realize that each of us operates from our own vantage point, or the theories that we construct as we go about our daily lives. The theories we build, in this sense, are not like the grand ideas tested by researchers (e.g., behaviorism, information processing, psychoanalysis) but the mental models or internal maps we use to navigate and make sense of our world and the things and individuals in it. We each construct our own theories based on our observations, but we also build theories based on what we hear or read. Social relationships matter and through dialogue and other means collective theories get built, spread, and get used to determine good and bad and normal and abnormal (Gergen, 2009). Collective theories gain momentum when they are turned into the stories that we tell. Stories become cultural artifacts and when they are repeated they become the norm and influence our values and behaviors. This includes our perceptions of disorders, who has them, and what this means. Consider the following example in which another culture, in this case the Maori of New Zealand, were seen as different simply because of their culture and its' traditions.

Psychology...has created the mass abnormalization of the Maori people by virtue of the fact the Maori people have been...recipients of defined labels and treatments...Clinical psychology is a form of social control...and offers no more "truth" about the realities of the Maori people's lives than a regular reading of a horoscope page in the local newspaper (Lawson-Te, Ano, 1993)

Foucault (1978; 1979) a proponent of helping people to understand their subjugation revealed the power of taken for granted practices. To Foucault, power is a coordinated cluster of relations and the specialized language a discipline develops creates binaries and divides. Instead of being seen as an individual we get placed into categories such as normal or abnormal. Disciplines also produce certain research procedures that privilege certain kinds of methodologies and scrutinize and classify us along their disciplinary lines. In other words, we become the labels that get assigned to us and the labels we acquire are used to control us. Disciplines gain power and influence public policy. Given this, let's look at mental disorders, like ADHD from a historical perspective.

In the United States, the first classification of a mental disorder occurred in 1840 and given its newness there were only a handful of distinctions. In 1930 psychiatry emerged and the perceptions of mental disorders began to grow. By 1938 the number of disturbances rose to approximately forty and since then, the number of disorders has risen to over three hundred and drug treatments have grown into a multi-billion dollar industry. If an individual has ADHD symptoms it is likely that he/she will be offered medication (Gergen, 2009).

Psychiatry has influence but another discipline neuroscience, has also come into play. In today's disorder-focused society neuroscience is influencing perspectives and this trend is likely to continue to grow (Maxwell, 2004). The past fifty years has seen an explosion of information about the brain offered to laypersons (Stamm, 2007; Stein, della Chiesa, Hinton, & Fischer, 2010). More findings are leading to more interest, more treatments, and as these get normalized and incorporated into policies and beliefs, fewer calls for restraint. When it comes to a disorder like ADHD more findings from are leading to more biological theories of it and more standardized treatments aimed at this cause. Neuroscientists are helping us understand how the brain of individuals with ADHD function but like McCabe and Castel (2008) and Weisberg, Keil, Goodstein, Rawson, and Gray (2008) showed these findings can be persuasive and misleading because they are new, diminutive, and alluring even though much of it is being overextended, misinterpreted, and simplified. If interpreted literally, and in isolation, findings from neuroscience will reduce learning, behavior, and emotions to biological processes alone. There are treatments, curricula, and products that purport to utilize findings from neuroscience to promote the learning and behavior of individuals with ADHD without any scientific backing.

Neuroscience is providing new and important information but if we are not careful it can also produce simplified and detached views of individuals, including those with ADHD. A Pygmalion Effect, or self-fulfilling prophecy is a groundless expectation that leads to behaviors that make the original expectation come true (Merton, 1948). In other words, we see what we expect and expect what we want to see. Remember the opening exercise where you recalled various perspectives of individuals with ADHD and the Maori people who were perceived to be abnormal and defined and perceived as such. Just because a characterization, or label becomes common does not mean it is right, fair, ethical, or just.

2. The ethics of ADHD

Considering ethical questions that arise when an individual is labeled ADHD is important because five million children (most of whom are boys) between the ages of 3 and 17 years and 8 million adults are diagnosed with it and this number is growing each year (U.S. Department of Health and Human Services, 2010). Thanks to better diagnosis and the spread of information, more and more children, adolescents, and adults are being diagnosed and as a result of identification more and more are being treated with pharmaceutical, social, and behavioral interventions (Barkley, 2005). Unfortunately, and too often, medication is often the only treatment many individuals receive. Medications like methylphenidate (Ritalin) and amphet-

amine (Adderall) slow the reuptake of dopamine in the brain and decrease the impulsivity and agitation of ADHD in 70-90% of cases. This quick and easy removal of symptoms is leading to more and more children at younger ages, and more and more adolescents and adults to be prescribed medication. But too often, medication is the only treatment many individuals receive despite the fact that absolute proof of its benefits is not available and little is known about its long-term effects (Farah, 2005). While there is no doubt medication helps many individuals with ADHD there is also no doubt that, for some, there are unintended consequences and side effects like weight loss, sleeplessness, and cloudy minds (Chau, 2007). Neuroscientists, physicians, psychiatrists, psychologists, and social workers warn that medication needs to be coupled with behavioral, social, and emotional support because alone it is not enough. In other words, medicine is a part of the puzzle but it is not a panacea. Locating an attention problem solely in an individual's brain and treating her/his brain with medication gets results but it does not offer a cure or help an individual truly understand him/herself. Medication focuses on changing behaviors. It does not increase self-awareness or heal a body or mind (Farah, 2005; Morse, 2006; Stein, della Chiesa, Hinton, & Fischer, 2010).

Medicating children can also lead to misuse of medication if they are not instructed as to its proper use. Current sales figures indicate that Ritalin and Adderall are not only being used by individuals with ADHD but by high school and college students without it. A survey by McCabe, Knight, Teter, and Wechsler (2005) discovered that as many as 10% of high school students and 20% of college students say that they have used prescription stimulant medications to increase their performance on a test and this use varies by ethnicity, gender, achievement, and location. White males who receive low grades, and are going to Ivy League colleges in the northeast with high standards, are the most likely to abuse stimulant medication. Interestingly, the stimulants they abuse often come from their peers who have been diagnosed with ADHD. Purchasing Ritalin is so prevalent among young adults it is referred as "kiddy coke" and "study buddies." While my intent is not to criticize or condone the use of medication, I realize medication helps many individuals, but I want to once again point out that if we do not slow our thinking down and become aware of our beliefs we will miss ethical questions like:

- How might the use of this stimulant cause psychological harm (e.g., lower esteem and motivation)? Will an individual on medication be robbed of his/her identity?
- When it comes to medication, what responsibilities are there and who is accountable for these?
- Does the label of ADHD promote standardized, quick and easy treatments?
- Is the label of ADHD promoting biases and stereotypes?
- How can we better the lives and learning of individuals with ADHD?
- How can individuals with ADHD be supported so they know how to compensate, navigate, and fit into the world?

- Do individuals with ADHD really need to change? How can characteristics and relational styles be respected rather than modified? How can individuals with ADHD become their own advocates?

Habermas (2003) notes that the careless use of biomedical advances can undermine the behaviors and passions of individuals, or change individuals so much they lose the ability to understand and take responsibility for their own lives. In the wake of neuroscience and biotechnologies it is important to step back, reflect, make good ethical decisions, and take action to ensure that individuals with ADHD are allowed to be themselves and have a voice in their development and lives (Stein, della Chiesa, Hinton, & Fischer, 2010).

3. Making ethical decisions

Now, the Star-Bell Sneetches had bellies with stars.

The Plain-Belly Sneetches had none upon thars.

Those stars weren't so big. They were really so small.

You might think such a thing wouldn't matter at all.

But, because they had stars, all the Star-Belly Sneetches

Would brag, "We're the best kind of Sneetch on the beaches."

With their snoots in the air, they would sniff and they'd snort

"We'll have nothing to do with the Plain-Belly sort!"

And, whenever they met some, when they were out walking,

They'd hike right on past them without even talking.

Dr. Seuss (1961)

The quote from *The Sneetches* by Dr. Seuss (1961) was written to oppose anti-Semitism and remind us about discrimination. As science moves forward the ethical challenges we will face will continue to grow and change. Neuroscience is seeping into all of our lives and changing what we know and think, including what we think about ADHD. However, making ethical decisions is often perplexing and sometimes stars on bellies become so common we fail to see them. When it comes to neuroscience how do we decide what to believe? How do we know what is right and wrong, what is just and unfair? Where can we find reliable information? Who's ideas matter? Neuroethics brings questions like these into focus and this is important because of the power of our beliefs. Neuroethics sits at the intersection between neuroscience and the ethical, legal and social implications it brings. To Racine and Illes (2006), neuroethics

focuses on the right and wrong, good and bad treatment of, perfection of, or unwelcome invasion of and worrisome manipulation of the human brain. Gazzaniga (2005, 2011) furthered this idea to include "the examination of how we as humans, want to deal with the social issues of disease, normality, mortality, lifestyle, and the philosophy of living informed by our understanding of underlying brain mechanisms." To Gazzaniga, neuroscience should help everyone develop a brain-based philosophy of life. But this is not easy because we tend to focus on ideas that align with our beliefs and allow our beliefs and emotions to cloud our judgment. To develop a brain-based philosophy we will need valid information and time for deep and reflective thought. Beliefs are not easy to change and neuroscience and ethics do not mix easily. Some findings from neuroscience are difficult to understand because they make us question the very fabric of who we are, who we can become, and how is best to live our lives. Moral questions have been around for centuries and after years of debate a human rights approach focuses on ensuring that everyone, including individuals with ADHD receive truthful information, a voice in their lives, the right not to be harmed, and the right to develop and grow. Now look back at the questions posed in the previous section and consider how these positions relate to individuals with ADHD.

In closing, I hope this chapter has made you reflect on your beliefs and ask questions as to how findings from neuroscience, medical science, psychiatry, and all of the other disciplines used to influence the lives of individuals with ADHD can be used fairly, for their good, and for the betterment of individuals with ADHD. Reason (1988) used the term "critical subjectivity" to explain the balance we should strive to achieve. To him we should critically reflect on what we learn and disregard what seems harmful and unjust. Gergan (2009) makes a similar point and reminds us to consider how beliefs stem from dominant disciplines, become obvious, bestow power, and cause some voices to be silenced. Kahneman (2011) notes the importance of slowing down and reflecting on our thinking and how information we focus on influences our thoughts and behaviors. Realizing that neuroscience can be persuasive and influence our beliefs opens the door for us to re-interpret and re-envision our perspectives of it. Moral questions arise when science's findings are applied to lives and we need to examine and change our theories, methodologies, and beliefs if they are wrong (Gopnik, 2009).

Questioning, of course, does not always provide automatic answers to moral issues but it does bring into focus the need to seek valid information and keep a critical eye on the facts we receive and trust. Findings and treatments from neuroscience can have positive or negative effects. Interventions can help individuals focus and behave. But if we are not careful they can also place stars on their bellies and rob individuals of their identities (Racine & Illes, 2006). The limits of methodology and the complexity of relations between research and practice take center stage in the challenges we face (Stein, della Chiesa, Hinton, & Fischer, 2010).

Progress is being made as the many chapters in this volume note, but we have much work ahead. To use neuroscience appropriately a causal chain of evidence needs to be clear and it is important to realize that when it comes to labeling, treating, and caring for individuals with ADHD we must realize:

- The best information from neuroscience is gathered with reliable and valid tools, replicated, and combined with personal insights.

- We need to become better consumers of information from neuroscience.
- We need to understand that the tools neuroscientists use are new, popular, rapidly changing, and persuasive. We need to understand these tools, the level of analysis they are able to perform, the reliability/validity of results, and what this all means to us in understandable and useable terms.
- Neuroscience cannot tell us how to treat individuals. However, it can be used to confirm, enrich, and refine theories and models of learning and behavior. Different vantage points or a consilience of disciplines (e.g., human development, cognitive science, neuroscience, behavioral science) are best (Wilson, 1998). A multi-voiced perspective leads to interventions that work.
- Even though information from neuroscience has grown, given insight, and become part of daily conversations we must not lose sight of the fact that it is an evolving and quickly changing field. We need to be fascinated but remain skeptical at the same time.

This chapter is full of questions, perhaps more than answers, but this is where I see us. Gains are being made and beliefs are being formed. Fortunately the Sneetches came to realize they were wrong.

But Mc Bean was quite wrong. I'm quite happy to say That the Sneetches got really quite smart on that day, The day they decided that Sneetches are Sneetches.

And no kind of Sneetch is best on the beaches, that day all the Sneetches forgot about the stars.

And whether they had one, or not, upon thars.

Dr. Seuss (1961)

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