



Just a Label? Some Pros and Cons of Formal Diagnoses of Children*

Diagnostic labelling of children who manifest learning, behavior, and emotional problems is on the rise. While appropriate diagnoses can be helpful, they come at a cost. And when a false positive diagnoses is made, the cost is incalculable.

What are Some Incentives Related to the Increase in Labelling Children?

- *Push for Academic Performance Drives Diagnosis.* Focusing on what they describe as “The ADHD Explosion,” Hinshaw and Scheffler (2014) explore the role of school policies -- particularly those pushing for improved test scores and graduation rates – as a major cause of soaring increases. That is, the drive for higher academic performance creates an incentive for schools to have underachieving students labelled (e.g., as ADHD and LD) to separate them out for accountability assessments and to provide extra assistance and testing accommodations.
- *Hope for Enhancing Treatment Access, Availability, and Effectiveness.* Diagnosis are used to indicate prevalence and incidence, and increases in such data are used to advocate for better access and availability of treatment resources, to guide treatment, and to stress the need for research and professional training.
- *Ease of Communication.* Diagnostic labels are used as the “verbal shorthand for representing features of a particular ... disorder” (Trull & Durrett 2005). Researchers, practitioners, training programs, advocates, third party payers such as insurance companies – all use labels to simplify communication in describing problems and needs, making decisions, discussing practices, interpreting outcomes, and so forth.
- *Knowledge that Comes with the Label can be Empowering.* For many parents, diagnostic labels help define the problems their children face and allow for greater understanding. Having a name for the condition means the parents can acquire knowledge, seek help, and take action to better the situation. One parent whose child was diagnosed with autism remarked that “labeling our child was the best thing we could have done, simply because it changed our children from bizarre and (sometimes) badly behaved to different but (mostly) well-behaved.”
- *Reattributing Symptoms to the Diagnosis can Buffer Self-Image.* The impact of learning, behavior, and emotional problems on self-image is summed up by Joanne Limburg (2011), an author and an OCD patient—“fighting a named enemy still takes it out of you, but it’s nothing like as enervating as trying to fight yourself.” The phrase “it is not me, it’s my ADHD” demonstrates how diagnostic labels allow some children to reattribute their difficulties to the diagnosis instead of blaming themselves. And for some, diagnostic labels protect them from self-blame and can help defuse charges of laziness or stupidity leveled by teachers, parents, or peers.

*The material in this document was culled from the literature and drafted by Joyce Cheng as part of her work with the national Center for Mental Health in Schools at UCLA. Key references used are cited in the reference list at the end of the document.

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The Dyslexia Debate: An Example of the Labelling Controversy

Akin to the long-standing debate over over-diagnosis of ADHD, the dyslexia debate exemplifies the controversies surrounding assignment of formal diagnostic labels to children and adolescents. Dyslexia is generally defined as an extreme reading problem caused by an inherited, brain-based, phonologic disability. The disability is characterized by slow reading, poor spelling, and difficulty sounding out words. Other often mentioned possible deficits include compromised organization, planning, and prioritizing skills, difficulty with numbers, and keeping time.

Advocates claim 20% of school-aged children and over 40 million adults have dyslexia in the U.S. Moreover, dyslexia frequently is described as coexisting with ADHD (e.g., it is suggested that from 25-40% of children with dyslexia also have ADHD). Valid data, however, on all this is not available. Thus, it is unclear how many actually have the disorder and how many have serious but commonplace reading problems that have been misdiagnosed.

What is clear is that anything that results in poor academic performance warrants attention. Without appropriate intervention, reading problems can persist into adulthood and severely restrict one's opportunities. Unfortunately, the current state of affairs is that appropriate help is mainly available to those who have been formally diagnosed and labelled.

Taking a radical position on the diagnosis of dyslexia, Elliott and Grigorenko (2011) claim that the term is meaningless and prevents many students from getting the help they truly need. In general, critics' raise the following concerns about the diagnosis:

- *No special intervention has been established for dyslexia.* That is, practices used with anyone who has a reading problem are as effective (and often ineffective) as those used with individuals diagnosed as having dyslexia.
- *Neglect of students without the diagnosis.* Critics worry that commonplace reading problems will be given short shrift. Moreover, while those diagnosed may escape attributions that they are just stupid or lazy, others with reading problems remain victims of such misattributions.
- *Inadequate definition and assessment.* The term dyslexia is inconsistently defined with problematic diagnostic criteria. Too often, it is diagnosed based on an extreme discrepancy between reading performance and IQ and ignores evidence debunking the link between IQ and dyslexia. [The discrepancy approach looks at reading performance to see if it is significantly lower than expected of someone with normal or higher IQ. Such a discrepancy only is an operational definition of the degree of underachievement.] Other tests may reliably assess correlates of reading problems but do not have diagnostic validity for proving dyslexia.
- *Conflicts of interest.* It is stressed that there are various parties who have vested interests in maintaining practices that diagnostically label children.

Some of these points have been challenged by advocacy groups such as the British Dyslexia Association and Dyslexia Reading Well. Such advocates state that:

- *Inconsistent definition does not justify abandoning the diagnosis.* As is the case with terminology in many fields, specialists do have disagreements about the term. However, it is emphasized that such disagreements do not disprove the existence of

dyslexia nor do they justify abandoning the diagnosis; moreover, studies attesting to the existence of dyslexia are offered.

- *Tests for identifying dyslexia are valid.* Advocates claim that tests assessing symptoms associated with phonemic awareness, pronunciation, fluency, speed and comprehension are valid instruments for diagnosing dyslexia. Specific examples offered include: *Comprehensive Test of Phonological Processing (CTOPP)* and *Dynamic Indicators of Basic Early Literacy Skills (DIBELS)*.
- *More diagnoses help address neglected children.* As a way to help more children who struggle with reading, advocates argue that more, not less, diagnosis of dyslexia is needed.
- *Buffer children from false attribution.* Cautions are made that downplaying dyslexia deprives students and families of relief from false attributions (e.g., lazy, stupid, bad parents).
- *Effective interventions for dyslexia.* Advocates claim that interventions that enhance phonemic awareness, fluency, and teach spelling rules are proven as specific treatments for dyslexia.

Note: Many of the same criticisms and counter-claims are raised for other labels such as learning disabilities (LD) and attention deficit hyperactivity disorder (ADHD).

What Are Some Negative Consequences of Diagnostic Labelling?

The following is a synthesis of major negative side effects related to labeling children and adolescents:

- *People see only the diagnosis, not the person.* A diagnostic label may come to negatively define the individual by focusing on the specific problem and downplaying many positive personal characteristics. That is, people may selectively attend to information that confirms the label while neglecting other information. For instance, parents and teachers may only attend to the times when a child diagnosed with ADHD acts restlessly but overlook other times when the child is calm.
- *All-or-nothing diagnosis.* Labelling of learning, behavior, and emotional problems tends to be categorical. An individual is viewed as either having a specific disorder or not, depending on decisions made about the criteria threshold set for diagnosis. In reality, however, such problems run along several continua (e.g., degrees of severity, pervasiveness, chronicity, degree to which the cause is environmental or stems from an internal disorder).
- *Diagnostic labels can lead to self-fulfilling prophecies and stigmatization.* Diagnostic labels not only change the reputation of an individual but also alter how other people treat the individual. For example, teachers who expect less from a student labelled as having a learning disability may be reluctant to challenge the student and thus limit his or her opportunities to learn. Consequently, the student may be less likely to perform well in school, which only confirms the diagnostic label. Moreover, others often tend to form negative attitudes about individuals who have diagnostic labels, and this can lead to negative actions toward the person (e.g., name calling, bullying).

- *Diagnostic labels may mislead understanding of cause.* For instance, the behaviors leading to a diagnosis of ADHD or LD may stem from an education system that does a poor job in accommodating students' differences and needs or from sleep deprivation among adolescents or any of a variety of other factors that constitute barriers to learning and teaching.
- *Medications with aversive side effects may be prescribed.* With increased diagnoses there is a corresponding rise in prescriptions for medication. Indeed, medications are often the first-line of treatment when some diagnoses are made. All medications are recognized to have side effects (some of which can quite debilitating). For instance, stimulants commonly used to treat ADHD may cause insomnia, suppressed appetite and growth, and other side effects affecting child and adolescent development. Prescription medications have also been linked to drug addiction and the feigning of symptoms to gain access to medications for personal substance abuse and black-market sales.

About Stigma

Stigma refers to a set of negative and often unfair beliefs that a society or group of people have about the characteristics, attributes, and behaviors of some people or things. Stigma can be cultural and chronic and can manifest as cognitions, affect, and behaviors experienced or expressed in social interactions. Stigma has been divided into three categories:

- *Public stigma* occurs when a large population collaboratively accepts a discrediting stereotype (e.g., about out-group members, about individuals who are different in physical, behavioral, and other intrinsic characteristics from the perceived norm). For example, out of the norm behavior leads to perceptions that the child doesn't fit in (e.g., observing that a child takes medication communicates that the child is different). Stigmatized children are less favored by their peers and are often hostilely rejected. Peer rejection, of course, can be particularly impactful.
- *Self-stigma* occurs when an individual internalizes negative stereotypes (often as a result of public stigma). This can lead to becoming overly fixated on one's diagnosis and neglecting one's positive attributes. Self-stigma not only affects self-image but also impairs social and emotional functioning and quality of life. For example, children frequently attribute their failure to meet their own and parental expectations to their diagnosed condition and are less likely to attribute successes to personal ability. Those on medication may perceive themselves as having to rely on medications to function normally, which can negatively impact self-image.
- *Courtesy stigma* refers to negative judgments that are made against family members or people close to the stigmatized person merely because of their association with that person. For instance, parents may be blamed for their child's conditions even when there is little evidence of poor parenting, risky behaviors during pregnancy, etc. Mothers are especially vulnerable since they often blame themselves for their child's problems.

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Center resources

- >Arguments About Whether Overdiagnosis of ADHD is a Significant Problem --
<http://smhp.psych.ucla.edu/pdfdocs/overdiag.pdf>
- >Schools and the Challenge of LD and ADHD Misdiagnoses --
<http://smhp.psych.ucla.edu/pdfdocs/ldmisdiagnoses.pdf>
- >Labeling Troubled and Troubling Youth: The Name Game --
<http://smhp.psych.ucla.edu/labeling.htm>
- >Common Psychosocial Problems of School Aged Youth: Developmental Variations, Problems, Disorders and Perspectives for Prevention and Treatment -- :
<http://smhp.psych.ucla.edu/pdfdocs/psysocial/entirepacket.pdf>
- >Determinants of Students' Problems --
<http://smhp.psych.ucla.edu/pdfdocs/determinants.pdf>
- >Countering the Over-pathologizing of Students' Feelings & Behavior: A Growing Concern Related to MH in Schools --
<http://smhp.psych.ucla.edu/pdfdocs/practicenotes/pathology.pdf>