

1 Social and Practical Considerations in Labeling

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1 Introduction

When children and adults in our society are perceived as having inordinate difficulty with their speech or language, a natural reaction is to ask whether those individuals have communication disorders (Barsky & Boros, 1995; Brown, 1995; Flower, 1984). More often than not, when this occurs in an educational setting for children or a medical setting for adults, a referral is made to a professional to determine whether there is indeed impairment, and how it should be addressed. If the difficulty is perceived as impacting communication or learning abilities, typically a cognitive, linguistic, or communicative impairment is identified and receives a label. Typically, the label is the product of some evaluative process that results in the assignment of a categorical diagnostic term.

This process of diagnosis is an accepted and even necessary practice when dealing with exceptionalities like communicative disorders. In order to provide services, to access fiscal resources, to obtain accommodations, or even to come to an understanding of how to address disabilities in a remedial process, an official diagnosis, an “objective” label assigned to an individual and his or her difficulty is often necessary. While it is commonplace to obtain these diagnostic labels and to employ them as if they were discrete, concrete, and fixed, this process is actually much more fluid and subjective than many professionals and lay people realize (Aspel, Willis, & Faust, 1998; Augustine & Damico, 1995; Carroll, 1997; Conrad & Potter, 2000; Fraser & Christopher, 2007; Wilson, 2000). The use of diagnostic terms like language disorder, childhood apraxia, dementia, learning disability, specific language impairment, autism, ADHD, auditory processing disorder, and many others, as labels for individuals and their impairments is not always objective or valid and, as a result, there are many possible consequences, some positive and some negative.

The object of this chapter is to demonstrate the impact of labeling via diagnostic categories, and how these labels result in various consequences. If the label or diagnostic category appears valid and is correctly attached to an individual,

positive consequences may accrue. Typically, the assignment of a valid diagnostic label enables entry into remedial programs such as special education in the schools, and assignment to therapeutic rehabilitation in medical and other clinical settings. However, there may also be problems. For example, some diagnostic categories themselves are suspect and merely function as mechanisms of current societal values, power, or control (Abberley, 1987; Conrad, 1992; O'Connor & Fernandez, 2006). If the label or category is invalid or if the individual is misdiagnosed, the resulting consequences are frequently negative. This chapter will discuss some of the mechanisms whereby lay, professional, and media claims help establish the practice of assigning diagnostic labels for various perceived impairments; particular aspects of the social context that contributed to the rise of these diagnostic categories and labels and some of the consequences will also be detailed.

2 The Impact of Labeling

Since the early 1960s, but especially since the widespread funding of special education in the United States, there has been a tendency to refer students to special education for language-based learning problems and for communication disorders of various kinds (DOE, 2002; Kretschmer, 1991; Richardson & Parker, 1993). Similarly, adults with various communication problems are also referred in order to initiate rehabilitation (Thompkins, Marshall, & Phillips, 1980). With each of these groups, the referral is followed by an assessment process that is intended to provide a diagnostic label. There have been numerous discussions on the process of evaluation in communication disorders. In general, the process is as follows: (1) a referral is made to the speech and language professional (SLP) by a teacher, nurse, physician, administrator, another professional, or family member; (2) the SLP reviews the referral and determines the types of information that should be collected; (3) an appointment is made for the SLP to evaluate the referred individual in a setting chosen by the professional; (4) a set of tests and other diagnostic procedures are chosen for the assessment session; (5) the assessment is completed at the appointed time(s); (6) the data from the assessment session is combined with any other data obtained by the SLP to provide diagnostic interpretation involving differential and descriptive diagnosis; and (7) a diagnostic label or category is assigned. As previously mentioned, once the diagnosis is assigned, then other decisions addressing educational and/or therapeutic issues are considered and implemented.

2.1 *Positive consequences*

Receiving a diagnosis in the form of a disability label may start a cascade of constructive consequences, if the diagnosis is an accurate one. The first constructive consequence is that the diagnosis may “transform an unorganized and unclear set of complaints and symptoms into a more organized and comprehensible disorder” (Balint, 1957). Once framed with a label, the disorder becomes easier

to conceptualize, discuss, and act upon. It is often the case that organized categories help all involved parties achieve greater understanding and communication about complex behavioral entities that are generalized by the labels (Darley, 1975; Leyens, Yzerbyt, & Schadron, 1994). In a study of children with ADHD, for example, one of the authors (Damico & Augustine, 1995) found that parents of many children eventually diagnosed as exhibiting ADHD often had nagging feelings that something was wrong but they could not put their finger on the problem. Indeed, based upon an interviewee's comment, the researchers in the study explained this phase of confusion as a period of "undefined malaise" (Damico & Augustine, 1995, p. 261) in which the parents did not know how to characterize their children's problems or where to turn for assistance. Once a diagnosis was provided, however, the parents felt that they had a better understanding and could proceed in a positive direction.

In line with the first consequence, once a valid and accurate label is obtained it can also "lead to opportunities and extra resources that are not available without a diagnostic label" (Gillman, Heyman, & Swain, 2000; Sutcliffe & Simons, 1993). As previously stated, many governmental regulatory bodies, educational remedial guidelines, and insurance providers require a standard diagnosis before treatment is provided. Federal and state special education regulations, for example, require official diagnoses before intervention is even planned. In the ADHD study just reported (Damico & Augustine, 1995), school systems tended not to orient to the needs of the students studied until a formal diagnosis was obtained. When the formal label was delivered to the schools, however, it acted as a catalyst. Various accommodations and services not previously offered to the child and parents now were provided. The label, therefore, had a reactive power over the schools, the parents, and even the children. This need to employ diagnostic labels to achieve such ends is not unique to ADHD. Numerous researchers have discussed this issue across many of the communicative and cognitive exceptionalities (Gipps, 1999; Glaser & Silver, 1994; Messick, 1984; Rogers, 2002; Rolison & Medway, 1985; Skrtic, 1991; Sleeter, 1996).

Positive impact, however, goes even further with regard to services provided. An appropriate label does not just create reactionary influences to provide service delivery; it also enables a discerning clinician to carefully prepare a treatment plan that is tailored to the needs of the individual now accurately identified and labeled. In doing so, having the valid diagnostic label may lead to specific intervention that will overcome the identified deficits (Archer & Green, 1996; Gross, 1994). In effect, as Brinton and Fujiki (see Chapter 6) have suggested, strong assessment resulting in an accurate diagnosis is essential for good intervention to occur. To use their metaphor, "you must know where you are going to plan your route."

Finally, an accurate diagnosis may have positive psychological and social consequences. For instance, individuals affected by various behavioral or medical symptoms can "legitimate their problems and achieve self-understanding" once an accurate and valid diagnostic label is provided (Broom & Woodward, 1996). The individuals with impairment can address feelings of confusion, isolation, or inadequacy and construct new identities and this, in turn, can assist in dealing

more effectively with their problems (Gross, 1994; Gus, 2000; Kelly & Norwich, 2004; Riddick, 2000). Therefore, the diagnostic label can have a substantial positive impact on the lives of the individuals with disabilities (Broom & Woodward, 1996; Damico & Augustine, 1995; Link, et al., 1989).

2.2 Negative consequences

Labels, however, may also have negative effects. This is particularly true if the applied labels are not valid, or if a valid label is inappropriately or incorrectly applied. The most obvious destructive consequence occurs when *an inaccurate label is applied*. There are two ways that this may happen. For instance, a school-child may exhibit communicative or academic difficulties that are not due to actual impairment, but is then misdiagnosed and labeled as disordered. In such a case, the mislabeled individual may be placed in special education or other remedial programs. Often this means that the curriculum is reduced so that more time and effort may be spent on content that is deemed most important and salient, or that specific learning strategies are employed that may be necessary for impaired learners, but that limit learning by average students. In these cases, inappropriate labeling provides poor opportunities for normal learners and the expectations directed toward the inappropriately labeled individuals are reduced (Brantlinger, 1997; Carrier, 1986; Connor & Ferri, 2005; Frattura & Capper, 2006; Rogers, 2002). Such situations often arise in contexts where students have language or learning difficulties arising out of cultural or language differences. When such students are referred for assessment, they are often mislabeled (Artiles & Ortiz, 2002; Cummins, 2000; Trueba, 1988; Wilkinson & Ortiz, 1986). Their difficulties due to differences are categorized as disorders, and they are placed inappropriately in special education (Connor, 2006; Hamayan et al., 2007; Magnuson & Waldfogel, 2005; Trent, Artiles, & Englert, 1998).

The second type of misdiagnosis occurs when an individual with a difficulty due to some actual impairment is identified as having a different impairment. In these instances the genuine impairment is not adequately addressed, remedial plans and the expectations for improvement may be inappropriate, and little positive change occurs. In research focusing on the impact of Asperger's syndrome, for example, Damico and Johnson (2005) found that nearly all of the identified individuals were initially misdiagnosed and their problems were not confronted for several years. These individuals had to endure school suspensions, transfers, and social and institutional isolation due to these misdiagnoses. Similar incidents have been described by numerous researchers across a range of disorders (Connor, 2006; Damico, 1988; Fairbanks, 1992; Fine, 1991; Hood, McDermott, & Cole, 1980; McDermott, 1993; Mehan, 1996). Labeling is particularly problematic in these cases due to the tendency to attach a stereotype to a label, and then to focus on the stereotypic behaviors in the labeled individuals regardless of the presence of other, even conflicting, symptoms (Madon et al., 2006).

Perhaps the most interesting, and potentially most serious, scenario for misdiagnosis occurs when the actual label applied is suspect, that is, when a diagnostic

category itself is invalid. As will be discussed later in this chapter, due to the subjective and fluid nature of labeling and application of diagnostic categories, a number of categories have been challenged in the research literature. These challenges focus on the construct validity of the diagnostic categories themselves, or indicate that the definitions used are too broad or subjective. For example, these claims have been made with regard to the recent definition of autism spectrum disorders (Bishop, 1989; Eales, 1993; Gernsbacher, Dawson, & Goldsmith, 2005; Gross, 1994), dyslexia (Erchak & Rosenfeld, 1989; Riddick, 2000; Weaver, 1998), learning disabilities (Brown et al., 1998; Coles, 1987; Gnys, Willis, & Faust, 1995; Kaufmann, Hallahan, & Lloyd, 1998; McDermott, 1993; Wilson, 2000), auditory processing disorders (Cacace & McFarland, 1998), attention-deficit/hyperactivity disorder (Bussing, Schoenberg, & Rogers, 1998; Conrad & Potter, 2000; Prior & Sanson, 1986; Reid & Katsiyannis, 1995; Searight & McLaren, 1998), and specific language impairment (Cole et al., 1995; Conti-Ramsden, Crutchley, & Botting, 1999; Dollaghan, 2004; Pena, Spaulding, & Plante, 2006; Ukrainetz McFadden, 1996).

While the most obvious harmful consequences may result from errors in labeling, the negative impact of the process is more complex and insidious. It must be remembered that labels are actually summaries of complex symptoms, a "mental shorthand" that plays into the human inclination to stereotype and make generalizations (Leyens, Yzerbyt, & Schadron, 1994). While this propensity does assist in communicating ideas underlying the labels, there is also the tendency to stop looking at the individual and start assuming that he or she is defined by the label and its characteristics. This assumption enables the professional to stereotype the unique aspects of the labeled individual so that "all children with a particular label are considered to be the same. This results in failure to notice and take into account personal strengths and particular difficulties" (Archer & Green, 1996). The consequence is "a reduction of individual differences and a limitation on the ways in which the individual is perceived and treated" (Lubinski, 2000; Madon et al., 2006).

Another negative consequence of labeling arises from the very practice of assigning a label. If the intent is to label an individual, then often there is an assumption that not only the symptoms but their origins actually exist within the individual being labeled. Consequently, there is a *predisposition to localize the problems within the individual* rather than to search for multiple factors and extraneous variables, including, for example, teaching styles, prior exposure to opportunities to learn and apply the targeted skills, and diversity issues in school children (Brown, 1995; Coles, 1987; Conrad, 2000; Forness, 1976; McDermott, 1993; Rapley, 2004). The decision to focus on intrinsic causal factors rather than extrinsic factors (or at least a combination) is likely a primary reason for the over-representation of various ethnic and socioeconomic groups in some aspects of special education (Cummins, 2000; Damico, 1991; McDermott & Varenne, 1995; McNamara, 1998). Treating labels as verification of intrinsic disability may also be based on the assumption that the source of all educational difficulties is related to causes that are intrinsic to students (Carroll, 1997; Gutkin & Nemeth, 1997). This assumption

is exacerbated by the general lack of familiarity that the general public has with the principles of language and learning in academic and communicative contexts.

Unfortunately, this belief in the primacy of intrinsic causal factors, exacerbated by labeling, frequently results in negative consequences. The label is often used to “explain away” the problem, so that if, for example, a child experiences poor teaching or unresponsive therapy, the propensity is to place blame on the child, not the methods or the teacher/therapist. The within-child deficit model makes for an easy and effective excuse (Brechin, 1999; Carrier, 1986; Kelly & Norwich, 2004; MacMillan & Meyers, 1979). As we will discuss later, this tendency to localize problems within the individual is a well-studied phenomenon in the sociology of disability. Within that literature it is referred to as the “medicalization” or the “psychologization” of performance and social problems (Conrad, 1992, 2000; Reissman, 1983; Searight & McLaren, 1998) and, because of labeling, there is a dramatic extension of medical and diagnostic psychological boundaries to explain numerous social problems (Barsky & Boros, 1995; Broom & Woodward, 1996).

Since most people are not oriented to the complexity of human meaning making and the importance of systems theory when addressing learning and communicative processes (MacWhinney, 1998; Nelson, 2003; Perkins, 2005; Thelen & Smith, 1998; van Geert, 1998), they are often willing to localize problems in the individual; it is simply easier to do so. To ignore the complexity is often soothing even if it is misdirected. The problem with using the label to reduce the complexity, of course, is that poor results ensue. Even if teachers or rehabilitative professionals are dedicated to the remediation process, their best attempts at assistance often are misguided and ineffective. In fact, research has documented that labeling with a focus on an intrinsic deficit model typically results in overlooking various environmental factors that may have generated or exacerbated the difficulty (Barsky & Boros, 1995; Boxer, Challen, & McCarthy, 1991; Brown, 1995; Coles, 1987; Dudley-Marling & Dippo, 1995). As Brechin (1999) discussed, “If the whole problem, *by definition*, lies *with the* individual [via a label], then our understandings and interventions start and stop with the individual” (p. 1; original emphasis).

Labeling as a process is often discussed within the sociological literature and it is frequently linked with assessment. This is due to the fact that most test development was designed for selection purposes (Glaser & Silver, 1994), that is, to determine who should be admitted to and benefit from what educational opportunity (Carroll, 1997; Glaser & Silver, 1994; Lohman, 1997). In order to create divisions for selection, however, a label must be supplied. Consequently, labels often become the handmaidens of societal biases and prejudices. Within this function, labeling has particularly damaging consequences. Assessment and the resultant labels assigned to many students are often used to create a kind of social stratification system, a way to keep people in their place (Artiles et al., 2005; Bradley & Corwyn, 2002; Cummins, 2000; Ogbu & Simons, 1998; Ruiz-de-Velasco & Fix, 2000). This labeling process and its resultant placements are a reflection of how power and control is exerted in assessment to fulfill societal roles of cultural and social reproduction (Abberley, 1987; Apple, 1982; Kavale & Forness, 1998; Loseke, 1999). The assignment of a label and the various consequences play a key

role in “cultural reproduction and social stratification” (Gipps, 1999). In his discussion of the impact of assessment and labeling theory in education in the United Kingdom, Broadfoot (1996) stated,

because assessment procedures are so closely bound up with the legitimization of particular educational practices, because they are the overt means of communication from schools to society and . . . the covert means of that society’s response in the form of control, assessment may be the most important of the three message systems. Assessment procedures may well be the system that determines curriculum and pedagogy and, hence, social reproduction. (1996, pp. 87–8)

Within the realm of special education, labeling students and placing them in remedial programs – even if only for a half an hour a day – effectively removes these students from “normal” schooling and places them in groups with students of similar ability for instructional purposes; they are socially isolated (Connor & Ferri, 2005; Fine, 1991; Gelb & Mizokawa, 1986; Gill & Maynard, 1995; Irvine & Berry, 1988; Messick, 1980).

Social isolation and stratification often prevents access to equal educational and occupational opportunity. Research in literacy employing a critical interpretivist frame, for example, has found that attaching labels like “intellectually disabled,” “mentally retarded,” and “dyslexic” significantly reduces the expectations and opportunities for individuals to become literate or to use their literacy skills to improve with practice (Kliewer, Biklen, & Kasa-Hendrickson, 2006). Similarly, Rapley (2004), employing discursive psychology, explored the actual process of limiting opportunity for those individuals labeled “intellectually disabled” through moment-by-moment interaction with care staff and other professionals. This tendency to limit access due to expectations formed by labels is one of the most damaging consequences of this diagnostic process. In education, those professionals who both assign the labels through assessment, and then help prevent access through various means (special education placement, tracking, limiting extracurricular activities) are known as “gatekeepers” (Deyhle, 1987; Mehan, Hertwick, & Meihls, 1986; Ogbu, 1978; Schuster & Butler, 1986; Thoits, 2005). The term is uncomfortably accurate in many instances.

Finally, labels can have *negative consequences for one’s psychological health and self-image*. While there are many instances of labeling helping to define individuals and letting them develop a workable self-image based upon identification with a disability label (see section 2.1), an opposite reaction can also occur. Research in “labeling theory” (Heise, 2007; Kroska & Harkness, 2008; Link et al., 1989; Rosenfeld, 1997) demonstrates that when individuals are labeled, the societal and cultural ideas associated with the disability in general and the label in particular become personally relevant to that individual and often foster negative self-feeling. These feelings can have a profound impact on the labeled individual.

An extensive investigation (n = 41) of the impact of labeling on individuals diagnosed as learning disabled, for example, indicated significant changes (Higgins et al., 2002). In this study there emerged a shared set of understandings

that involved reaction to the label and then coming to terms with the diagnosis. Conceptualized by the researchers as five stages of acceptance, the labeled individuals struggled with their diagnoses for years. After the second stage of receiving the label, stage three and four involved a long process of trying to understand what the implications of the label was for each person personally and functionally. In stage three, understanding/negotiating, there were struggles to understand the label and how it impacted school and social spheres. Importantly, this was a time when stigmatization was most problematic (Gelb & Mizokawa, 1986; Gergen & Davis, 1985; Goffman, 1964). The fourth stage, compartmentalization, impacted the actual practices of the labeled individuals. Through their actions over a long period of time, these individuals tried to minimize the importance of the label by adapting their preferences and activities so that they could minimize weaknesses and maximize strengths. While this was viewed as a positive adaptive strategy, it nevertheless resulted in reduced opportunities and limited activities. The fifth stage, transformation, indicated a period when the label and disability was reframed into a “positive force in their lives.” Interestingly, this stage was not achieved by many individuals, even after a 10-year period.

A number of other researchers have investigated labeling theory or a variant of it once individuals are labeled as “learning disabled” (Bogdan & Kugelmass, 1984; Bos & Richardson, 1994; Foster, Schmidt, & Sabatino, 1976; Hellendoorn & Ruijsenaars, 1998). One study in particular (Forness, 1976) investigated several kinds of behavioral reactions to labeling overall. In these and other studies (Damico & Augustine, 1995; Damico & Johnson, 2005; Higgins, 1980; Hood, McDermott, & Cole, 1980; Klasen, 2000; Livneh & Antonak, 1991; Livneh & Evans, 1984; McDermott & Varenne, 1995) the negative impact of labeling on psychological and social functioning has been demonstrated for many individuals.

3 Concerns with the Process of Labeling

Given the fact that labeling has a long history of application in education, medicine, and the social and psychological sciences, that it arises out of the human propensity to generalize, stereotype, and construct meaning, and that there appear to be both positive and negative consequences of labeling, the process is well ingrained in our sociocultural context. Progressively, however, as social science addresses complexity and has established developmental and epistemological orientations that are less positivistic in nature and focused more on social constructivism (Bruner, 1991; Danziger, 1990; Gergen & Davis, 1985; Goodman, 1978; Iran-Nejad, 1995; O’Connor, 1998; Shuell, 1986), there have been growing concerns about the process of labeling. Within the constructivist framework (see section 4 below), labeling is seen as too subjective and vague, especially given its power in the spheres of social action (see section 2). Foremost in the litany of concern is the linkage of labeling with assessment.

As a widespread practice, assessment is a fairly recent phenomenon (Broadfoot, 1994; Gipps, 1999). In the context of the attempt to develop a more scientific

foundation for the discipline of psychology at the beginning of the twentieth century, assessment was seen as a way to demonstrate both scientific principles and practical utility (Gould, 1996; Mills, 1998). When psychometric theory was developed in tandem with the creation of intelligence testing (Bernstein, 1996; Goldstein, 1996; Lohman, 1997), there was an allure of the objective and scientific. This was a time of behaviorism and a belief in positivism and it was taken for granted that the assessment of human abilities, skills, and proficiencies could be effectively accomplished through the development of test instruments. The use of quantification and statistical formulae helped advance this perception. However, to construct testing with sufficient statistical power, especially regarding reliability indices, a strict standardization was required that impacted test design, item selection, administration procedures, and scoring criteria of the tests; these efforts to boost technical reliability often had a negative effect on the construct validity and the practical and clinical impact of the tests (Cronbach, 1988; Damico, 1991; Goldstein, 1996; Lohman, 1997; Lubinski, 2000; Messick, 1984). This resulted in ineffective assessment tools that were, however, typically perceived to be valid and effective.

Especially since the 1970s, research in various fields of education, psychology, and the social sciences has demonstrated that the assessment process, and tests designed to accomplish assessment, are not scientific and objective activities: human assessment is not an exact science. Like other social endeavors, assessment is not objective but, rather, value laden and socially constructed (Broadfoot, 1994; Broadfoot, 1996; Damico, 1991; Greene, 1994; Lohman, 1997). As stated by Gipps (1999, p. 370), "in assessment, performance is not 'objective'; rather, it is construed according to the perspectives and values of the assessor, whether the assessor is the one who designs the assessment and its 'objective' marking scheme or the one who grades open-ended performances." In disciplines and institutions that have traditionally supported assessment with norm-referenced and standardized tests, these tools and their practices of using discrepancy formulae, and procedures and processes that focus on component skills rather than authentic skills have been challenged (Boxer, Challen, & McCarthy, 1991; Fletcher et al., 1998; Greene, 1994; Gutkin & Nemeth, 1997; Lubinski & Humphreys, 1997; Snyderman & Rothman, 1987; Sternberg & Grigorenko, 2002; Wentzel & Wigfield, 1998).

Most significantly, governmental changes are also recognizing the problems with traditional assessment tools and the labeling process. In remedial public education in the United States, the major regulatory instrument is the Individuals with Disabilities Education Act (IDEA). In the most recent re-authorization of IDEA, there have been some rather significant changes that support the need and implementation of different assessment frameworks and processes.

Because of continued disenchantment with the traditional approach to special education, the recent IDEA re-authorization discussed several obstacles to implementing effective special education services (Hamayan et al., 2007). Among the obstacles cited were that implementation of the act has been impeded by a disproportionately high number of referrals and placements of "minority children" in special education, and by the application of discrepancy models using

inappropriate tests that often result in these disproportionate placements. To address these and other issues of concern, the 2004 re-authorization requires a number of innovations. For example, the document provides for more specific incorporation of “early intervention services” rather than using assessment tools with discrepancy models to place students into special education. That is, the regulations have been modified to address the needs of the students and to determine eligibility for special education services; pre-referral interventions (a kind of dynamic assessment) rather than tests and other assessments will be employed; the focus directly shifts from evaluation with testing instruments to intervention potential as the primary determinant of placement. Additionally, the new documents do not require test scores to make placement decisions into special education. In fact, in the 2004 version of IDEA, references to “tests” have been changed to “assessment materials” in an attempt to downplay the more traditional testing paradigm.

In addition to the necessity of using testing and assessment procedures that are now suspect in order to obtain a diagnostic label, there are other emerging concerns about the process of labeling. For example, there is now more documentation that labeling within special education functions more as a structural framework for social reproduction than as a remedial model (Carrier, 1986), and that the models used for labeling in the so-called soft diagnostic categories of special education are more influenced and associated with socioeconomic indicators than with proficiency (Gelb & Mizokawa, 1986).

While the perceived difficulties with the use of labels may appear surprising from a positivist and behaviorist perspective, a brief discussion of labeling as a social process may clarify this issue. The remainder of this chapter will focus on labeling as viewed from the social theory of social constructivism.

4 Labeling as a Social Process

Earlier in this chapter (section 1) we claimed that while it is “commonplace to obtain these diagnostic labels and to employ them as if they were discrete, concrete and fixed, this process is actually much more fluid and subjective than many professionals and lay people realize.” This is because the assignment of labels based upon clinical and psychiatric diagnoses are historically and culturally situated. That is, they may appear, expand, or contract over time depending on how society and the involved professions form and hold particular beliefs and ideologies (Cooksey & Brown, 1998). To understand this statement, it is beneficial to view labeling from the perspective of social constructivism.

4.1 *Social constructivism*

Social constructivism can provide important insights into the process of labeling. An important assumption is that knowledge does not exist as an external reality; there is no “prefabricated” world of knowledge waiting to be discovered or

acquired (von Glasersfeld, 1989). Instead, cognitive development and any subsequent knowledge acquisition is an internal process within both ontogenetic and social dimensions. This starting assumption has informed two strands of social constructivism. One strand focuses on the ontogenetic and personal axis and has been best advanced by two of the leading developmental intellectuals of the twentieth century (Piaget, 1970; Vygotsky, 1978). For our purposes the second strand, focusing on the social dimension, will be discussed. This definition of social constructivism is derived from the sociology of knowledge and focuses on the collective construction of social reality; it is not to be confused with the focus in psychology and genetic epistemology on the influence of social constructivism on the cognitive growth and the creation of a personal epistemological reality.

It can be argued that the primary influence within the sociology of knowledge for the establishment of social constructivism was *The Social Construction of Reality* (Berger & Luckmann, 1967). Recognizing the primacy of systematicity in any successful society, the authors discussed how this systematic and comprehensible social world was created; how a society forms and holds beliefs and social constructs. Unlike the work of many epistemologists, this text focused on the creation of knowledge from the collective perspective, that is, on the construction of what passed for knowledge in a society. Although the individual was, of course, the agent of this creation, it was the knowledge generated by the group that held sway. Berger and Luckmann's book discussed the tendency of individuals to construct meaning in their world; to use their symbolic capacity to create ways to achieve comprehensibility that is constructed, sustained, and transmitted to others in their collective contexts. By constructing meaningfulness and integrating it into their everyday contexts, individuals establish their beliefs, their assumptions, and the understandings of the situations within which they function. Importantly, however, these same meanings, when accepted and agreed upon by a collective of individuals (a society), take on an autonomous reality in the world as social "realities," "facts," and institutions that are maintained over time within this society. That is, subjective meaning constructed by individuals becomes objective social and epistemological "facts" within the society. In effect, the ideas, practices, values, assumptions, and even the institutions of the society, those things accepted as "givens," are constructions that have been established and reified by various social processes and mechanisms.

These same processes operate when institutional and adjunct bodies of knowledge and belief are constructed. Using psychotherapy as an example, Berger and Luckmann discussed how institutional and discipline-specific "realities" are constructed as well. They wrote that, "Since therapy must concern itself with deviations from the 'official definitions' of reality, it must develop a conceptual machinery to account for such deviations and to maintain the realities thus challenged. This requires a body of knowledge that includes a theory of deviance, a diagnostic apparatus, and a conceptual system . . ." (1967, p. 113).

In a similar fashion, the "official definitions," assumptions, and labels used in our related fields of study are also constructed and then mutually agreed upon. As long as the social and institutional "realities" serve our needs and do not

conflict with other social facts and behaviors, we can proceed within our pragmatically constructed reality. The process for accomplishing this task is the thrust of the Berger and Luckmann text; they analyze the social construction of reality overall and then demonstrate the impact via numerous specific examples. As they state, "And in so far as all human knowledge is developed, transmitted and maintained in social situations, the sociology of knowledge must seek to understand the processes by which this is done in such a way taken-for granted 'reality' congeals for the man in the street" (1967, p. 3). Within this framework, it is understood that labeling as a process is a conceptual mechanism socially constructed to accomplish a number of objectives, many of which have been previously discussed in this chapter.

Those who criticize social constructivism sometimes charge that it denies the independent reality of anything; that it implies that everything is socially constructed. As O'Connor (1998) states, however, Berger and Luckmann, and other constructivists, make no such implication. These individuals are not trying to undermine the physical world or many forms of knowledge; rather, they are trying to understand the mechanisms that underlie the tendencies and practices of society and the social world. The recognition and reliance on an external physical reality can be noted in the following excerpt from *The Social Construction of Reality*:

Man is biologically predestined to construct and to inhabit a world with others. This world becomes for him the dominant and definitive reality. *Its limits are set by nature*, but once constructed, this world acts back upon nature. In the *dialectic between nature and the socially constructed world* the human organism is itself transformed. In this same dialectic man produces reality and thereby produces himself. (Berger & Luckmann, 1967, p. 183; emphasis ours)¹

The process of social construction whereby "facts" and "realities" are created by the social mechanisms and have an actual impact on the beliefs, assumptions, and practices of social agencies has been demonstrated in a number of theoretically and research-oriented tests and studies. In *The Social Construction of Literacy* (Cook-Gumperz, 1986), for example, reality and how it is presented and addressed in language arts classrooms is examined with a focus on the mechanisms by which individuals continuously reproduce social order. This affects treatment plans, pedagogical assumptions, practices, grouping of students, and evaluation. Within the social constructive framework, learning occurs not by recording information but by interpreting it. Therefore, instruction must be seen not as direct transmission of knowledge but as a component of the dynamic meaning-making process (Bruner, 1986, 1991; Cook-Gumperz, 1986; Iran-Nejad, 1995; von Glasersfeld, 1989). From a constructivist perspective, just as observers construct reality, learners construct their own knowledge, but always through a dialectic process with their culture (Airasian & Walsh, 1997; Bruner, 1990; Goodman, 1978; Iran-Nejad, 1995; von Glasersfeld, 1987).

This focus on the constructive nature of learning has had an important impact on various facets of education and educationally related fields and it is at the

level of the collective's construction of social reality that the primary implications for education research can be found. For example, issues revolving around what topics and subjects are considered to be most important to teach, what it means to have learned something, who are considered to be the important consumers of education, and how we negotiate the learning process on a daily basis, are all dependent upon our constructive processes (O'Connor, 1998). Mehan, for instance applied a constructivist framework to one of the first detailed analyses of classroom activity. He focused on the impact of social constructivism and ideas and assumptions resulting from it on how lessons and teaching interactions are structured (Mehan, 1979), on the impact of our assumptions and actions, including labeling, on students in special education contexts (Mehan, Hertwick, & Meihls, 1986), and on the construction of learning disability in a special education placement meeting (1996). Similarly, social constructivism has played a role in our changing focus away from behaviorism and toward cognitivism (Danziger, 1990; Mills, 1998; O'Connor, 1998; Shotter, 1993; Shuell, 1986), away from a component-oriented model of literacy instruction (Geekie, Cambourne, & Fitzsimmons, 1999; Goodman, 1994; Smith, 2004; Wells, 1986), and in a current reevaluation of principles underlying special education (Bogdan & Kugelmass, 1984; Dudley-Marling & Dippo, 1995; Gelb & Mizokawa, 1986; Gindis, 1995; Kavale & Forness, 2000; McDermott, 1987; Rogers, 2002).

4.2 Social constructivism and labeling

There are a number of ways that social constructivism is manifested to impact the process of labeling. A brief discussion and several examples will demonstrate the subjective nature of this process.

4.2.1 Medicalization Perhaps the most salient demonstration of a mechanism of social construction and its impact at the societal level involves what has been termed "medicalization theory" (Williams & Calnan, 1996). This explanatory mechanism involves the impact of society and its values acting through a particular societal institution – medicine – to create new diagnostic categories or to redefine or expand old categories according to current sociocultural values and beliefs (Halpern, 1990; Zola, 1972). In addition to the extension of medical boundaries, in the process of medicalization non-medical problems become defined and labeled as medical problems, usually as disorders or illnesses. For example, over the past 40 years there have been a large number of new medical categories that did not exist before that time. Medical categories and labels like attention-deficit/hyperactivity disorder (ADHD), anorexia, chronic fatigue syndrome, fibromyalgia, and post-traumatic stress disorders have all been established in this time frame and other categories have been redefined to create expansions (Conrad & Potter, 2000; Erchak & Rosenfeld, 1989; Halpern, 1990; Rosenfeld, 1997).

One example of redefinition through medicalization involves cognitive changes associated with high old age. Until a few decades ago, the notion of senility was accepted both socially and medically, and highly "successful" aging, that is, a

person living into their eighties or nineties without noticeable deterioration of memory, orientation, or other cognitive skills, was considered the exception rather than the norm. However, a combination of social and medical factors have moved what was formerly understood as senility firmly into the realm of dementia (in public and media discourses more often than not identified with Alzheimer's disease), that is, a disease process, socially constructed as something that is, by definition, not part of "normal" aging (even though the well-established major risk factor for a diagnosis of Alzheimer's disease is old age). While some researchers argue that conflating the low-functioning end of a normal distribution with a genuine disease process may be less than helpful in leading to an understanding of either normal or pathological aging, age-related "dementing" is, in public discourses in the United States and other industrialized nations at present, framed virtually exclusively within a disease model (Fox, 1989; Guendouzi & Müller, 2006; see also Chapter 26).

Conrad and Potter (2000) have provided excellent demonstrations of medicalization for category expansion with Adult ADHD. Their work details a number of societal factors (e.g., emergence of publications aimed at lay readers that heralded the new category, research published with one function but reinterpreted by the media and advocacy groups for their purposes (Zametkin et al., 1990), major news media with their own spin on the issue, popular magazines, organizational stakeholders like Children and Adults with Attention Deficit Disorders (Ch.A.D.D.) and manufacturers of primary drugs for ADHD) to create a perception that is then followed by the medical institutional response. Conrad and Potter detail a set of early claims regarding ADHD in adults that started gaining some attention, and then a strong movement into the public sphere when news organizations began to profile ADHD in adults. Over time, and with the collaboration of sympathetic professionals (Brown, 1995), diagnostic institutionalization occurred through increased attention and support provided by professional publications, research journals, and changes in the medical diagnostic criteria (see below). As detailed by many researchers (Cherkes-Julkowski, Sharp, & Stolzenberg, 1997; Conrad, 1976; Damico & Augustine, 1995; Reid, Maag, & Vasa, 1994; Searight & McLaren, 1998), once the category is institutionalized, the stakeholders then engage in various forms of verification to stabilize this diagnostic category. For example, the condition of Adult ADHD is a convenient way to medicalize academic or occupational underperformance of young adults in a competitive society. In a social context that includes an orientation to drug management of many conditions (Conrad and Potter, 2000, employ the term the "Prozac era"), a focus on genetic foci to explain behavioral and societal tendencies, and the rise of managed care so that a diagnostic label may be needed to receive remuneration for services sought or provided, medicalization is more easily understood.

The problem, of course, is that since this is a constructive process, often more influenced by social rather than biological factors, many of these diagnostic categories may be complicated by ambiguity and subjectivity and this lack of definitional rigor may result in various types of problems. Most relevant to the

clinical context is the concern over the authenticity or the construct validity of the various diagnostic categories (see section 2.2). In his book *Illness and Culture in the Postmodern Age*, Morris (1998) has discussed this possibility for a number of illnesses and diagnostic categories. He has suggested that ADHD and some other socially constructed diagnostic categories (e.g., Alexithymia, Gulf War syndrome, chronic fatigue syndrome, multiple personality disorder) may be defined as “postmodern illnesses.” This term refers to categories of illness or behavioral states that are vaguely and subjectively defined and that are controversial with regard to their legitimacy as real illnesses. Accordingly, these diagnostic categories often puzzle mainstream medicine, are sensationalized and augmented by the popular media, are confusing to the general public, and have a tendency to be abused (Morris, 1998).

Morris explains this pattern of attention and abuse by suggesting that, rather than being legitimate and objective disease states or disability conditions, these specific illnesses represent changing patterns of human experience and affliction that are shaped by the convergence of biological states, cultural beliefs, and social actions. For example, identification of a child as exhibiting ADHD may often be less the result of a neurological or biological condition and more due to a developing tendency of society to treat teachers’ and parents’ anxieties regarding childhood by routinely drugging children into good behavior; that is, social control through medication (Damico, Müller, & Ball, 2004). Whether an accurate depiction or not, the constructive nature of these categories and labels cannot be ignored.

The medicalization of social problems is a complex process, rather than a discrete step; it is better conceptualized in terms of degrees of medicalization. Further, this constructive process is usually a collective action. Although various non-professional groups and individuals can propose the creation of new or expanded categories or labels, it usually takes sympathetic professionals for success (Brown, 1995). The final requirement for the establishment and application of socially constructed labels and diagnostic categories does, in fact, rely on professional collaboration and this may be referred to as “legitimization” or “professionalization.”

4.2.2 Diagnostic legitimization The collaborative process of diagnostic legitimization, whether considered a component of medicalization or a separate process in its own right, occurs when professional institutions provide a legitimate cover for the socially constructed categories. Examples of this relevant to our current discussion are some of the diagnostic categories that are enshrined in the American Psychiatric Association’s *Diagnostic and Statistical Manual* or the World Health Organization’s *International Classification of Diseases*. Once diagnostic legitimization occurs, many lay people and professionals then treat the diagnostic category as an objective “fact” or “reality.”

While the American Psychiatric Association’s *Diagnostic and Statistical Manual* (DSM) and the World Health Organization’s *International Classification of Diseases* (ICD) are often considered as standards for objectivity in medical and behavioral

diagnoses – tools that employ rigid standards and objective criteria that are above reproach – many diagnostic categories or labels that are listed and described in the DSM or ICD do not employ objective criteria, nor are they indicators of objective conditions. Rather, like all diagnostic labels, they are social constructions influenced by various social and cultural factors (Coles, 1987; Cooksey & Brown, 1998; Gernsbacher, Dawson, & Goldsmith, 2005; Kroska & Harkness, 2008; Kutchins & Kirk, 1997; Reid & Katsiyannis, 1995; Reid, Maag, & Vasa, 1994; Rutter & Tuma, 1988; Searight & McLaren, 1998). The DSM is a document that has been described as a mechanism that can be used to “secure psychiatric turf” (Kirk & Kutchins, 1992). Numerous researchers have suggested that the DSM is a way of sanctioning the diagnostic categories by providing apparent “objectivity” by using the socially constructed authoritative voice of psychiatry. What is lost in what Cooksey and Brown (1998) referred to as this “diagnostic project” is the reality that the DSM (and ICD) are based upon the same variables that are involved in all social constructions of institutional touchstones: sociocultural values and assumptions, political compromise, scientific evidence, and material for insurance forms.

The subjective and fluid nature of many of these diagnostic categories has been widely discussed in the literature with reference to various diagnostic categories (Aspel, Willis, & Faust, 1998; Augustine & Damico, 1995; Barsky & Boros, 1995; Broom & Woodward, 1996; Brown, 1995; Conrad, 2000; Cooksey & Brown, 1998; Jensen, Mrazek, & Knapp, 1997; Kaufmann, Hallahan, & Lloyd, 1998; Kavale & Forness, 1998; Kirk & Kutchins, 1992; Kutchins & Kirk, 1997; Marshall, 1996; Prior & Sanson, 1986; Reid & Katsiyannis, 1995; Reid, Maag, & Vasa, 1994; Rutter & Tuma, 1988; Scott, 1990). Given recent claims for significant increases in the incidence of autism in the United States, an example for how social construction influences the process of legitimatization in autism and how this very process creates the perception of an “autism epidemic” is especially illustrative (Baker, 2008; Gernsbacher et al., 2005).

Gernsbacher, Dawson, and Goldsmith (2005) convincingly argue that the “autism epidemic” does not really exist, and discuss the role that the DSM and societal influences play in the increased incidence of autism, owing to changes in the DSM diagnostic criteria due to various socially oriented factors, in different editions of this major diagnostic manual. For example, in the DSM-III a diagnosis of autism required satisfying six mandatory criteria (“DSM-III. Diagnostic and Statistical Manual of Mental Disorders,” 1980) but in DSM-IV (“DSM-IV. Diagnostic and Statistical Manual of Mental Disorders,” 1994) the diagnosis is fulfilled by meeting only 50 percent of 16 optional criteria. Further, the criteria themselves were made more vague and inclusive by changes in the phrasing employed. In the DSM-III one of the criteria was manifestation of “a pervasive lack of responsiveness to other people” (1980, p. 89), while the closest criterion to this in the DSM-IV is that an individual must demonstrate “a lack of spontaneous seeking to share . . . achievements with other people” (1994, p. 70). Similarly, the 1980 mandatory criteria of “gross deficits in language development” and “bizarre responses to various aspects of the environment” were changed to “difficulty sustaining a

conversation” and “persistent preoccupation with parts of objects” respectively. Finally, the numbers of diagnostic categories for autism were changed from two in DSM-III (infantile autism and childhood onset pervasive developmental disorders) to five in DSM-IV (autistic disorder, pervasive developmental disorder not otherwise specified, childhood disintegrative disorder, Rhetts syndrome, Asperger’s disorder). Given these changes to the diagnostic criteria, it is not surprising that there appear to be many more diagnoses of autism over the time period discussed. Indeed, the new and milder categories or variants of autism appear to account for 75 percent of the new diagnoses (Chakrabarti & Fombonne, 2001) and when other socially driven changes (e.g., establishment of threshold and sub-threshold symptoms, a decision to co-diagnose, attempts to identify children at progressively younger ages), are also considered, it is no wonder there appear to be significant increases in incidence. The point, however, is that led by advocacy groups championing more relaxed and inclusive criteria, the “reality” of autism has changed according to social considerations. Discussions on the role of social variables in reconceptualizing autism, its causes, and its incidence may be found in the work of various researchers in the history and epidemiology of autism (Baker, 2008; Fombonne, 2003; Gernsbacher, Dawson, & Goldsmith, 2005; Silverman, 2004).

5 Implications and Conclusion

As professionals, we often operate within our sociocultural milieu without a critical analysis of our practices and the conceptualizations that underlie them. The problem with this, of course, is that we might become blind to our poorly justified practices, or we might ignore new or inconsistent data that could potentially undermine our assumptions about important processes like labeling and its impact on our practices. Since we are agents of our society and, as such, are defined by the same realities, practices, and assumptions as others, this is a natural tendency. Within our sociocultural milieu, however, we must also remember that we fulfill a role as agents of rehabilitation and scholarship. As Brantlinger (1997) has argued, this requires us to be more diligent in how we operate within our sociocultural and political contexts; our priority should not be the sociocultural or epistemological status quo. Rather, our priority should be as advocates and agents of positive change for our patients and clients.

There are at least three implications that should emerge from this realization of our role as advocates when dealing with the social complexity of labeling. First, we should *acknowledge and strive to deal with labels as complex phenomena*. Labels are not simple, direct, or objective. They are powerful sociocultural artifacts that transmit biases, assumptions, and facts. They are also catalysts in the construction of both positive and negative consequences. To effectively elicit the positive consequences and reduce the negative ones, we must recognize the constructive nature of these labels and the fact that they are often context-dependent, and at least partly context-created. For example, a quantifiable impairment such as

age-related reduction in hearing (even within “age-normal” limits) may constitute a career-destroying handicap for the conductor of a symphony orchestra, but not for someone in a different walk of life. Consequently, as clinicians we should not simply reify labels and consider them as “absolute,” objective categories. Rather, we should carefully consider how important it is to properly identify actual difficulties, determine the severity and context-dependence of the labeled difficulties, and avoid the tendency to label without addressing the complexity and obtaining definite and objective data to support a diagnosis.

Second, we should strive to avoid the most basic negative consequences of labeling that occur when relying solely on the label. Rather, we should strive to *thoroughly describe the difficulties that underlie the label*. This means not only carefully documenting actual behaviors and their impact on the context, but also determining how the context impacts the behaviors and whether there are other emergent factors that must be adequately described and addressed (Perkins, 2005). Rather than orienting to symptoms to determine labels we should orient to the skills, abilities, and strategies that can determine functional adequacy within the relative communicative and learning contexts. Darley (1975) had this in mind when he suggested that, when diagnosing aphasia, we focus on ability not labels, and his chapter “Aphasia without Adjectives” still offers relevant advice nearly 35 years after its publication.

Finally, we must be *circumspect with our current conceptualizations and practices*. By employing a more sociocultural orientation when focusing on diagnosis and labeling, we can turn our analytic powers to the very contexts and assumptions that we often take for granted when working with labels, so that we can better serve the needs of our clients.

The focus of this chapter has been the process of labeling and how it is impacted by sociocultural processes and how, in turn, our practices are then impacted by the labels that we employ. There is, of course, much support in the professional literature for the process of labeling. Such support tends to focus on the positive consequences while downplaying the negative ones. As competent professionals, however, we must consider the potential for both. Certainly, the practicing professional should strive to reduce the negative consequences of labeling whenever possible. As we discussed in an earlier publication (Damico, Müller, & Ball, 2004), we need to be able to contextualize a diagnosis or label, and then we should strive to discover the reality behind the label and the individuality of each client’s condition. This will enhance our service delivery in the field of speech and language disorders.

NOTE

- 1 We may also note in passing that summarizing all of humanity under the label “man” may be considered by many to reflect a social construction of human reality in need of rethinking.

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