

THIS ARTICLE SETS OUT to describe a survey that was conducted in 1970 and then replicated over thirty years later. The original survey, conducted by one of the authors of this article, asked 147 questions in relation to the attitudes of mothers of children or young people with Down's syndrome. It was conducted in southern Germany in 1970 but never analysed or published. Replication of the survey in 2003 was designed to enable the authors to explore how attitudes had changed between these two time periods and to posit some thoughts about why these changes had occurred, especially in the light of the changes in availability of prenatal diagnosis.

Unfortunately there is very little detail, either about the process of undertaking the original survey or about whether any other information on factors which could influence family attitudes was recorded. With the second survey, the authors describe using a number of screening techniques to ensure valid questions. This reduced the number of questions in the survey from the original 147 to 78. They then also reduced the number of received responses analysed from their second survey by over a third to exclude questionnaires with a strong bias of 'Desirable Responding' (this excludes responses that appear to aim at giving the answers the respondent thinks are wanted rather than being a true reflection of the respondent's views) and there is nothing in the article to suggest that similar techniques were used with the first survey. This causes me concern. The differences that they describe and attribute to attitudinal changes could well be attributable to the different approaches as to the validity of questions and responses taken in the two surveys.

In addition, the discussion describes some societal and service changes that have occurred in the intervening years, such as the growth of parental support groups and the increasing number of public appearances of actors with Down's syndrome, but ignores others, such as changing professional attitudes or the greater availability of educational provision. Nor is there any reference to the Nazi

'euthanasia programme' of the 1940's, which eliminated many people with developmental disabilities, and the profound impact this had on German family attitudes for many decades afterwards. This would certainly still be influencing in 1970 in Germany the attitudes of parents of young people born between 1950 and 1967 (and the professionals who advised and supported them). Any discussion that does not address these wide ranging issues appears limited and superficial.

Having questioned the research methodology, I, as the sister and mother of people with Down's syndrome who were of an age to be part of the survey population if resident in the relevant location, also question the overall conduct and purpose of the research. The questions it appears to be attempting to address, about attitude change since the introduction of prenatal screening, leave me with a major question. Why would anyone conduct research of this type without also looking at the attitudes and language of health professionals? This is for two reasons: one is that I believe professionals, and their approaches to working with parents, have a very significant input into the attitudes of parents; and the other is that personal experience suggests that professionals' knowledge of the positive aspects of life with Down's syndrome is often minimal.

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LANGUAGE, LABELS AND DIAGNOSIS: AN IDIOT'S GUIDE TO LEARNING DISABILITY. By A. McCLIMENS. *Journal of Intellectual Disabilities*, 11(3),

257-266, 2007. **REVIEW AVAILABLE ONLINE**
@ www.srvip.org

Reviewed by Ray Lemay

THE AUTHOR IS FROM THE UK and at the outset one must understand that the expression “learning disability” refers to what we, in North America, would commonly call mental retardation or intellectual disability or developmental disability, etc., and that’s pretty much what the article is about. It is about the problematic language, labels and diagnoses that are used to identify people who have cognitive impairments, and how such labels do not helpfully describe such people.

The author briefly relates the history of naming people with cognitive impairments, showing that names have changed with cultural and scientific fashions. The author reminds us that naming and categorizing are done by those in power (and who, more often than not, are not of these categories of people). Typically, people are usually quite careful about the names they give the groups they themselves belong to (Optimists, Lions, Doctors, Professors, Conservatives, Liberals, Republicans, Democrats, etc.). Obviously—unless one is trying to name a new rock band—one would think twice before calling one’s group the “idiots,” “schizophrenics” or “autistics.”

Language is dynamic and quite naturally evolves over time, which is why Shakespeare is somewhat of a challenge to read today. For instance, technical terms invented with the Mental Deficiency Act of 1913 gave us a new classification for people with cognitive limitations. The once scientific sounding “idiots,” “imbeciles,” “feebleminded” and “moral defectives” have since enriched the vernacular with new pejoratives. McClimens provides us with a bit of history for the term *idiot* which was borrowed from classic Greek, where it is a word that helps distinguish between the expert and his subject as in doctor and patient (idiot). Of course, since then, idiot has been colored in an obviously much more negative way. In other

words, over time we all get to be idiots but would rather be called patients, though we all have come to know the feeling.

The story of inventing new, usually negative, words to name people who happen to be devalued is compellingly described in a chapter by James Maddux (2002), in which he argues that the *Diagnostic and Statistical Manual* (DSM) of the American Psychiatric Association invents a whole new unremittingly negative vocabulary for categorizing people. These new words are to be used to name others, not ourselves. He proposes that the DSM is a social construction, that it is not a scientific document but a social one.

Maddux writes that mental disorders are not real, in a sense that they “do not exist and have properties in the same manner that artifacts and viruses do” (p. 16). “Like these other social constructions, our concepts of psychological normality and abnormality are tied ultimately to social values—in particular, the values of society’s most powerful individuals, groups and institutions—and the contextual rules for behavior derived from these values” (p. 16). Though the DSM purports to be descriptive, it is rather prescriptive in that it tells us how we should and shouldn’t lead our lives. The DSM has gone from 86 pages in 1952 to almost 900 in 1994 and the number of mental disorders has increased from 106 to 297. The author then describes how DSM categories are established.

“First we see a pattern of behaving, thinking, feeling, or desiring that deviates from some fictional social norm or ideal; ... we then give the pattern a medical-sounding name, preferably of Greek or Latin origin. Eventually, the new term may be reduced to an acronym, such as OCD (obsessive-compulsive disorder), ... the new disorder then takes on a life of its own and becomes a disease like entity. As news about ‘it’ spreads, people begin thinking they have ‘it;’ medical and mental health professionals begin diagnosing and treating ‘it;’ and clinicians and clients begin demanding that health insurance policies cover the ‘treatment’ of ‘it’ ” (p. 17).

McClimens tells a similar story, that of the expression “learning disabilities” as it is used in England, where the term learning difficulty has also become widespread in replacement of mental retardation.

Where learning disability is a relatively benign expression in North America, in the UK the impact of the label is more dramatic, “... when an individual labeled with learning disability attends a health care appointment they are always in danger of having their disability treated before any more localized or urgent symptoms are taken into account” (p. 261). It is almost as if ‘learning disability’ in England has the same social consequences as ‘mental retardation’ in North America. Indeed, sticking such labels on an individual is identity defining; it is what we might call an “ascribed role” (Lemay, 1999), such as one that comes complete with mostly negative stereotypes and expectancies. Citing another author, McClimens tells us “disability is a social category, which legitimates, or at the very least condones, the disempowerment of people with particular mental or physical attributes” (p. 262).

McClimens suggests that it is language that makes the difference and devalues people, but the author seems to misunderstand the story he is telling. Thinking back to 1916 and the new scientific terms of idiot and feeble-minded, it is language that becomes tainted by its association with a group of very devalued people. This is the point of devaluation as described by SRV, where devaluation is a force on its own. From a Social Role Valorisation (SRV) perspective, it is a group’s devaluation that leads others to choose a negative technical vocabulary that then over time becomes increasingly pejorative. McClimens proposes that language is a causal agent of devaluation, when in fact it is merely a reflection of the very real devaluation that occurs. Language provides a window on devaluation, but it does not (at least on its own) cause devaluation. Language gets caught up in the vicious cycle of devaluation.

But words are supposed to serve a purpose, and even negative words can help us understand and

identify that which we need to speak about. The author tells us that careful attention to language can make a difference in our understanding of learning disability or mental retardation, but the fact of the matter is that McClimens has not really illuminated the issue. After reading this article, we still don’t know what intellectual disability, mental retardation, learning disability or learning difficulty might be. There is no description or definition. These are words that have vague meanings and values (note simply how learning disability means something quite different across the Atlantic); however, we are no closer to describing what it is.

In an enlightening passage, the author quotes a man with a learning disability. Harry Green gives us a description of what it means to have a learning disability. “Put another word used for it ... people call you backward ‘n’all. Think that’s what they mean, backward of learning, of being slow. Means so many different words, doesn’t it? Daft. Dyslexic. Potty. Stupid or idiot. Whatever you can call it” (p. 263). This is certainly inelegant, quite negative, but here, finally, is an attempt at true communication, grappling with the problem of defining.

The vernacular is usually good enough for communication with and between people of valued classes. The professional behavior of coining a new vocabulary about a given group is quite likely going to end up being negative and is a sure sign that devaluation is occurring. All of this also suggests that living and language are non linear multiple feedback loop systems, and whatever we do about words is bound to have some kind of impact, but we might not be able to predict on what and how. The author’s suggestion that we need to be more humane and respectful in our written and spoken descriptions of people is a nice sentiment, but it is unlikely to be helpful if the underlying devaluation is not addressed. However, working from an SRV perspective, with its emphasis on attributing and crafting valued social roles, should encourage one to embrace the vernacular and make technical labeling irrelevant.

Mathematicians have suggested that an infinite number of monkeys, typing on an infinite number of typewriters over an infinite amount of time, could eventually and quite randomly type up the works of Shakespeare. Given the contrived nature of the negative-speak that inspires professional labelers, one would suspect that only a definite number of monkeys working on a definite number of typewriters for a definite number of years could come up with a DSM.

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ROLE DEVELOPMENT: AN EVIDENCED-BASED INTERVENTION FOR INDIVIDUALS DIAGNOSED WITH SCHIZOPHRENIA IN A FORENSIC FACILITY. By V.P. SCHINDLER. *Psychiatric Rehabilitation Journal* 28(4), 391-394, 2005. **REVIEW AVAILABLE ONLINE @ www.srvip.org**

Reviewed by Ray Lemay

VICTORIA SCHINDLER WRITES THAT “individuals diagnosed with schizophrenia often have deficits in developing and/or maintaining social roles and their underlying tasks and interpersonal skills. Commonly available treatment such as medication and activity programs alleviate symptoms and promote improvement, but may not address the development of social roles or the skills nested in these social roles” (p. 391). The author thus highlights the differences in outcome goals of different programmatic initiatives. Some programs of intervention seek symptom reduction or functional improvement; indeed O’Connor (2001) in her doctoral thesis describes how successfully treated (symptom free or at least controlled) ex-psychiatric patients live lives of abject poverty and social isolation in the community; in the community each of these individuals had a role identity that could be summed up as ex-psychiatric patient, nothing more, nothing less. However, in this article, the author describes an approach where a role development program went beyond merely reducing or controlling symptoms and addressed issues that touched upon the quality of life experiences and conditions of inmates.

Since you are reading this journal, why not tell someone else about it? We believe Social Role Valorization is an important tool that concerned individuals can use to address social devaluation in people’s lives. As someone who shares that belief, encourage others to read and subscribe to the only journal dedicated to SRV. Information available at http://www.srvip.org/journal_general.php.