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The World in 3D: Dyslexia, Dysgraphia, Dysnumia

Dana Raphael, Ph.D.
The Human Lactation Center, Ltd.
Mike Salovesh, Ph.D.
Northern Illinois University
Martha Laclave
Michigan State University

The voices you will hear are those of anthropologists with invisible learning disabilities who made it in a profession that places heavy demands on learning abilities. In this paper, we will present some life experiences that, because of our behavioral dislocations from expected norms, placed unusual challenges upon us as individuals and our journey through the academic process by which one becomes an anthropologist.

JOURNEYING THROUGH LIFE WITHOUT A MAP

Learning disability (LD) is a general term for a group of disorders associated with a multi-faceted mix of atypical brain patterns. Those of us with LD exhibit one or more of the following kinds of difficulties: dyslexia, great difficulty in learning to read; dysgraphia, great difficulty in learning to write, in the sense of making marks on paper; dysnumia, great difficulty in learning to handle numbers in the simplest mathematical calculations. LD is usually confirmed with discovery of wide disparities in performance of different kinds of tasks. For example, a high school student with excellent grades but whose handwriting resembles that of a typical third grader. For administrative convenience, many school systems operationally define LD as some specified difference in percentile ranking on tests designed to measure specific areas of ability and performance. When LD is so defined, the paradoxical effect is that it is closely associated with what is recognized as "high intelligence" or "strong academic ability." As LD people quip, "If you have LD, you can't afford to be dumb."

LD folks may also have organizational deficits such as great struggle in putting ideas into orderly outlines; or a series of snarls in hearing, sense of location and body presence, or hand-eye coordination. Attention Deficit Disorder (ADD) is also associated with these syndromes.

Although most of us with LD have difficulties that are dominant in one area of learning, the presence of one usually means a strong probability of having notable problems in others, sometimes all of the areas discussed here. This suggests that there may be a single focus for LDs. A large body of anecdotal evidence suggests that some part of the LD complex is gene-related. Genetic studies appear to have localized individual genes involved in these disorders.

ANECDOTAL EVIDENCE

Every adult has occasional lapses that seem similar to the patterns of LD. For those who are not familiar with these disorders, it is easy to ask, "What's so special about your case?" One kind of answer is illustrated at the level of personal experience. All of us have good coordination while typing or playing the piano or guitar. We have extensive vocabularies and the habit of reading widely. Two of us have written numerous professional articles and several books.

Mike Salovesh

Here, Mike Salovesh is speaking: "The salient part of my LD is dysgraphia. I have trouble writing my own name. When we first caught on to my dysgraphia, my wife noted that when I sign a check I first wiggle the pen in the air just above the paper, making practice strokes resembling an orchestral conductor waving a baton. Actually making marks on the paper requires a tight focus of attention and strong determination. I prepare for it. I `will' myself to relax, take a breath, and plunge in. I feel the tension all over my body and I don't return to normal breathing until sometime after I finish. Every time I am disappointed in the gap between the marks I intended to make and what actually appears on paper."

Mike's son, John, emulates dysgraphia perfectly when he describes his actions. "When I go to write anything down, I have to think how each letter looks. Then I trace it on the paper, and go on to the next one. It's never automatic. I can't just write things down. It takes so long that by the time I write a word I sometimes forget what word comes next."

Salovesh's voice again: "I discovered that I had LD when I was over 50 years old. All that time I had searched for ways to accommodate my disability without even knowing I had it. For a long time, I tried every variation of pens and pencils I could find. It was as if I believed that if only I could find the proper writing implement, all my troubles making marks on paper would disappear.

"Luckily, I learned to type in seventh grade. I still have not learned to write comfortably in cursive script. When I began studying anthropology, I learned on the most efficient typewriters I could obtain until 1982 when I started using computers as word processors just about the time I learned of my dysgraphia.

"Early in my studies, I learned that trying to take written notes guaranteed frustration and failure. When it came to reading, it was easier to buy books than to take notes on library copies. Instead of note cards, I built stacks for books next to the typewriter. Whenever I wrote a scholarly work, I used the placement of these books to lead me to relevant citations as needed. I learned to carry the content of the lectures I heard in my head for long periods and until their content was fully assimilated.

"Repeated practice helped me to recall full conversations verbatim. When I began fieldwork, my professors wanted me to send them copies of my field notes, so I produced them by dictating into a tape recorder. On the long field trips, my wife transcribed those recordings in the field.

"These unwitting accommodations got me around some, but not all, of my problems as a graduate student. I had the good luck of never having to depend on essay exams for my total grade. In courses that included both an essay exam and some other written material, I never got a grade higher than C plus. When I could write in the privacy of my study and take as long as I needed, my grades were never lower than A minus. Once I worked out what I wanted to say in a term paper or take-home exam and assembled all the necessary references, I would write the final copy at the rate of one page every eight to twelve hours. Writing a sixty page MA thesis, after I finished analyzing the materials, took me sixty 14-hour days.

"The departmental comprehensive qualifying exam was different. I had to practice writing under exam conditions until the process was close to automatic. Each Wednesday night for six months I would take a three-hour section extracted from an old department exam. I typed my answers, of course. Four other students joined me in a study group and did the same thing. Each of us graded carbon copies of another's answers and then we discussed how our answers might have been improved. These intensive rehearsals plus permission to type the exams got me through. The professors were happy not to read bad writing.

"When I applied for admission to Ph.D. candidacy, some of my professors had such grave doubts about the adequacy of my written field notes that they strongly opposed letting me go on. To me, field notes are intended as a memory jog rather than a record of everything I know. Most of what I know is still carried in my head, not on paper. In fact, I wrote my entire doctoral dissertation without writing anything on note cards!

"The faculty resolved their problem with me by assigning for my committee two members who favored admission and two who did not. It wasn't easy but it worked and I sailed through their close inspection without any requests for rewrites or substantiation."

Dana Raphael

Now listen to Dana Raphael's story. "My experience with Columbia University was astonishing. Without realizing what I was doing, I had talked several of my professors into allowing me to do independent research projects in lieu of exams. And it worked. Combined with class writings, my grades were never outstanding but I passed. As for the written comprehensives, I thought I did well. A week later, I called Joseph Greenberg, my professor, to learn the results. I can still hear his voice clearly, `Not only did you fail, you are a disgrace to the department.' I was devastated. I knew the material and believed I had done well with the exams. Even then it never crossed my mind that something might be wrong.

"It took me years to understand why Dr. Greenberg responded to my exam as he did. My spelling, usually phonetic, must have seemed remarkable to him. I paragraphed ideas something like stream of consciousness and quite artistically believing that my purpose was to arrange the material so that it looked good on the page.

"I knew I was in trouble and the decision I made was strictly intuitive. I obtained every question that had ever been asked on any comps at Columbia and from as many kind department secretaries from as many other universities around the country as possible. I wrote the answers to all of them. My husband, a writer/editor, then corrected all the spelling. (No blessed Spell Check then.) Single thoughts were formed into sentences, then into single idea paragraphs, creating a briefing book of 400 single spaced typewritten pages. Besides this, I memorized over 200 cards with information about as many cultures grouped in culture areas.

"For two years, many, many hours every day, I did nothing but type and re-type these paragraphs until exam time. I passed. When I discovered no more than a decade ago that I was dyslexic, I was stunned. Then I realized that many critical moves in my life had been affected by my undiscovered disorder. This revelation opened up a new way of looking at and listening to myself, my activities, my expectations and some painful moments in my life.

"For instance, as a pianist, I needed six hours of practicing each day so I was put into a private school. In Mrs. Hale's warm and simple `Home School' we were read fairy tales and I was allowed to do arithmetic all day long if I chose. No one ever forced me to do spelling or geography. As a teenager, I auditioned for the Juilliard School of Music and it seemed I would be accepted without question. Then came the last hurdle. Madame put music on the staff in front of me and said, `You now play pour moi.' I froze. I could not read music I had not heard. Only recently have I realized that had I chosen another instrument or become a singer, any opportunity where I could sound mainly one note at a time (for example the fiddle), I might not be an anthropologist today."

Martha Laclave

"Meeting Dana Raphael and Mike Salovesh on my first trip to the American Anthropological Association annual meetings while still an undergraduate proved fortuitous. They became part of my discovery about my so-called disabilities. They warned me of their trials in academia and shared their methods for getting by. They quickly became my resource for support and friendship. We became angry together and resolved our feelings about our shortcomings in a field that demands the observed details and research in written ethnographies.

"My history both mirrors and mediates theirs. My progressive hearing loss (from age 13) put an end to my focus on music in high school. At age 21 I was examined by a minimum of 21 specialists for chronic ear pain and hearing problems. I explain the story by telling others how I stopped counting the number of doctors I had because I did not want that number to exceed the number of years I have lived. Final diagnosis: I have auditory perception disorders. I am hearing impaired. (See Estroff 1993 regarding concepts of chronicity.)

"During this medical history I was also reported to have dysgraphia and ADD. When the specialists asked to see a sample of my writing, I brought in a recent paper and was able to watch the process they went through trying to discover how I think. Several specialists told me I had to be `re-taught' how to write. So during my last undergraduate semester I drove to a hospital several times a week to be `re-taught.'

"The person who was most helpful was my undergraduate advisor who tried many approaches and spent innumerable hours helping me improve my writing skills. Most important, he believed me. I was lucky. Many people never get that far. I still use the guidelines he typed on a half sheet of paper describing, so simply, how to construct a paragraph from my perspective.

"So, unlike my two fellow anthropologists, I approached graduate school with an identity as `disabled' and that was OK. For example, I wrote about 30 drafts of my application to grad school. Because I had defined myself as someone who needed special attention, I actually, and most gratefully, had a professor read and comment on every one of them.

"In the last semester of my undergraduate career, I was fitted with my first hearing aid. I had a group of disabled friends. I became active in the community. Importantly, I began to realize that disabilities are also issues of human rights. I became an activist.

"My graduate seminars revolved around issues of resistance, representation, power, and a multitude of ways of describing, critiquing and discovering what was really going on. I became interested as to why disability is not included in discourse about race, ethnicity, gender, nationality and other identities.

"Disability is not recognized as a human rights issue by anthropologists. This failure to link the relationship of the disabled community to larger cultural patterns is analogous to a failure to link such relationships as gender and ethnicity to contemporary structures of power. Lennard Davis has helped elucidate the problem: `The fact is that disability as a topic is under-theorized - a remarkable fact for this day when smoking, eating a peach, or using a bodily orifice are hyper-theorized. Because of this under-theorization, which is largely a consequence of the heavy control of the subject by medical and psycho-social experts, the general population does not understand the connection between disability and the status quo in the same way many people now understand the connection between race and/or gender and contemporary structures of power. I hope that as a result of the efflorescence of studies on disability from within the community of people with disabilities the day is not far off when the majority will dismiss the current dominant view as \`antiquated' and find it hard to believe that such a regressive understanding of the body could ever have been held by intelligent, progressive people. (Davis 1995)

"Self-awareness led me to the particular approach I have taken to my current research in South Africa on the age of onset of disability, social movements and community formation. Many of my colleagues question how I function in the field, suggesting that my hearing impairments would make interviewing more difficult. They do not ask how my being American, white or female affects the context of interaction. My speech, tone and pitch have remained the same. I often receive the dubious compliment Irving Kenneth Zola (1982) and others with disabilities have reported: \`You know, I never think of you as handicapped.'

"For me, being a disabled researcher has helped because, as Stone and Priestly explain, \`The inherent power relationship between researcher and researched is accentuated by the unequal power relationship which exists between disabled people and non-disabled people in the wider world (1996: 700).' The people I work with often freely ask, \`What happened to you?' or state without embarrassment, \`I think I know why you don't cover your hearing aids with your hair.' Or, they might query, \`Are all buildings in America like this [meaning are they accessible]?' The worries about my hearing impairments are mostly those of my colleagues. My worries are about writing. As it happens, my field notes are good. They turn out to be methodical and creative, not uncommon in those of us who are learning disabled.

"Knowing the experiences of Dana Raphael and Mike Salovesh has brought me both fear and comfort. Since this article is anecdotal, I will relay a final story. We chose Raphael to read this paper at the American Anthropological Association's annual meetings and we, the two other authors, sat at the back of the room. As an after-thought, Raphael said, \`I bet there are people in this room who have learning disabilities. Let's see. Please go like this if you are one of the LD folk,' she asked gesturing with her right hand over her eyes, her left hand raised and her shoulders brought forward in embarrassment. About a third of the audience shook their heads in agreement, raised their hands or bowed their heads."

COMPARING OUR EXPERIENCES

Despite surface similarities due to a common condition, each of us have great differences with regard to how LD affects us.

One of us can handwrite perfectly well without any phobia or fear and prejudice against writing in public or in private. All enjoy the computer for it moves almost as fast as our thoughts. But Raphael is frustrated when the word processing program speaks in to her from its microcosm in odd lingos. Stumped, it forces her to click HELP and then deal with reading bits and pieces of instruction. Far better, she feels, when the action is declared `illegal,' would be for the application to provide her with appropriate prompts much as one needs to work out a word puzzle. Although we each manage far better now, doubt not that these strictures have left many scars.

Salovesh remembers being brutally humiliated by his peers. In second grade, Raphael was told, "Go back to your seat you stupid little girl. You don't know how to read." "Because I later attended a non-traditional primary school," she said, "I wasn't destroyed. In fact, my own family thought it amusing when I signaled right and said, `Go left, left.' My first son, taking his brain patterns from his father, won all the spelling bees. The second, inheriting my tendencies, never was diagnosed and, even with tutoring, had difficulty."

Each of us seems to have found a host of obstacles under specific cultural settings and from them have come these generalizations about these internally hidden impairments.

1. Brain different people need to become their own most intense listener, powerfully sensitive to what is happening inside their body, their brain. (See Johnson 1956, a masterful and readable early work on self-reflexive listening, pp. 169-178.)

2. Most cases of childhood LD go unidentified or are co-opted as something else. Thus, many adults with LD do not even suspect that it may be the basis of some difficulties in their lives. The most common conclusion outsiders reach about any LDers with whom they deal, is: "Those folks are lazy."

3. Many `insiders' come to have low self-esteem or to spend a great deal of time in introspection, because the outside view of them is repeated so often it takes on a self-fulfilling plausibility. People with LD that has not been identified usually carry a horrifying burden of guilt about their disabilities because they see them as character flaws.

4. Many teachers and health practitioners deny that the underlying problems exist and attack the integrity of those who claim to have LDs. Those who have been competently diagnosed as having learning disabilities must demonstrate, again and again, that there are a combination of symptoms that come together in a pattern that makes a coherent package. That package recurs far too often to be attributable to mere accident. It is a recognizable set of symptoms.

5. If and when its presence is diagnosed, LD still is an invisible condition. Its carriers do not move in wheelchairs or use other aids that can be seen. Their bodies present no recognizable signs of any impairment or disability. Having an invisible impairment carries annoying disadvantages. It is very

difficult to seek reasonable accommodations under the Americans with Disabilities Act or justification for special education.

6. People with LD manage to make some sort of adjustment to the world around them. It may not be the most effective or the most efficient solution to their particular problem(s), but most find a way to function on par with those around them. Accommodation is frequently accompanied by concealment. After all, we hear accusations of stubborn, obstinate and worse so often that passing as normal or even `faking' can come to be more important than getting help.

7. Anthropologists might look for the kinds of intuition and other such skills that are adaptive in non-writing nor reading focused cultures.

We are aware that, at times, what has been described here is culturally constructed and/or medicalized. However, our anecdotal evidence makes it pretty clear that learning disabilities also have a biophysical, perhaps sex-linked, genetic foundation that seems to be hereditary.

We have also been exploring whether or not there is a correlation between those who are "self-reflexive" anthropologists, such as we tend to be, and these learning disabilities. Certainly it was so for Dana Raphael whose own experiences became the basis for her fieldwork. She failed to breastfeed her first child and wrote a dissertation on the need for `mothering the mother' in order to prevent lactation failure.

Salovesh continues to work on the unsuspected, the invisible and the deniable aspects of cultural processes such as dyslexia. He says his new project on LD and this personal journal of three persons in the world of 3Ds (dyslexia, dysgraphia, dysnumia) evolved essentially from what he saw as commonalties in patterns and life experiences as a result of these disabilities. Laclave's concern with hearing/ADD/dyslexia has been described. And we figured there must be other anthropologists out there like us.

Each of us continues to make clever compensations in our search for ways to reveal, with stealth, our undisclosed selves to others, never forgetting the behavioral representations of us and the so often unkind responses to us by colleagues, health professionals, students, family and friends, who never dreamed we had a problem. This realization leads to one very humbling question: If such a life-changing revelation was not apparent to us, trained observers that we are with very introspective personalities, what else, as anthropologists, do we miss?

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