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The True Meaning of Research Participation

I've been doing a happy dance lately, ever since learning that a manuscript I contributed to was recently accepted for publication in *Psychological Science*. In fact, I'm just about as excited as I was 25 years ago when I received my first editorial acceptance. Only this time, I didn't receive the notification directly; rather, it was forwarded to me by another author, because on this manuscript I'm merely the third of four coauthors. The first author conceived the study, initiated the data collection, supervised the statistical analyses, and wrote the first draft. The study empirically challenges conventional wisdom and provides a powerful demonstration of the level and nature of autistic intelligence. The first author, Michelle Dawson, is autistic.¹

Like many autistic people, Ms. Dawson is very interested in the topics in which she's interested. She reads so prodigiously that she's known as the living PubMed around my lab. At least once a week, we find ourselves emailing her to ask if she knows of "any other studies on . . .," and within an hour, we receive an annotated bibliography, much of it from her memory. She's a polished writer, and most of all, she's a scrupulous thinker. These days, I wouldn't fathom submitting an article (or even one of my APS Presidential columns) without first seeking her no-holds-barred critique.

Ms. Dawson is not the only autistic who takes a keen interest in autism research and who reads voraciously, thinks analytically, and writes prolifically on the subject. Amanda Baggs, an autistic who relies primarily on augmentative communication for speaking, maintains the blog, "Ballastexistenz," which means "ballast-life," a term from the German eugenics program that targeted disabled people. One recent post presented an analysis of the autistic children in Leo Kanner's original sample, implicitly demonstrating how some autism researchers and the general public have incorrectly used the term "Kanner's autism." The analysis emulated a grade-A answer on a doctoral prelim exam.

Joel Smith, an autistic who often relies on augmentative communication devices for speaking, maintains the website, "This Way of Life." On the site's associated blog, Smith

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recently provided a tutorial on probability that would rival any introductory statistics lecture. Another autistic's blog, "Natural Variation," which "dispels junk science in the autism field, scrutinizes questionable treatments, and exposes stereotypes and demeaning characterizations," recently explicated the placebo effect observed in the multimillion-dollar NIH-funded studies of secretin² and did so with precision far beyond that found in the studies' peer-reviewed articles.

Listservs, Yahoo groups, and even Second Life are teeming with autistics' informed and articulate discussions of autism research — from persuasive deconstructions of their putative lack of mirror neurons, empathy, and theory of mind, to provocative hypotheses about atypical minicolumns, Purkinje cells, and 2D:4D ratios, to book-club-like discussions of the classics. Press releases, conference presentations, and journal articles are devoured and digested, sometimes with burps as simple as "no sh*t, Sherlock" (in response to a *Nature Neuroscience* publication of mine).

However, autistics are almost never consulted by autism researchers (thereby violating the mantra of disability rights, "Nothing About Us, Without Us"), and often they are explicitly excluded. Ms. Dawson has documented Canadian research conferences that barred autistics from attending but curiously welcomed parents of autistic minors as expert contributors.

Why haven't autistics' own voices been heard? Why haven't autistics been as actively recruited to participate in all aspects of the research process as they've been recruited to participate as research subjects (even posthumously by donating their brain tissue)?

Perhaps it's assumed that autistics just wouldn't be able to handle high-level research. If so, someone ought to tell Vernon Smith, who was awarded the 2002 Nobel Prize in Economics (alongside APS Fellow Daniel Kahneman) for pioneering the field of experimental economics. And somebody better alert Richard Borchers, who was awarded the

¹See Sinclair (1999; http://web.syr.edu/~jisincla/person_first.htm) to appreciate my respectful use of the term "autistic" rather than "person with autism."

²Secretin is a peptide hormone. Its alleged connection to autism was popularized by media reports of an autistic child whose development was attributed to a secretin infusion he received during a routine endoscopy.

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mathematics equivalent of the Nobel Prize — the Fields Medal — in 1998. Both academics are diagnosed autistics.

It takes just a cursory stroll through history to view the shocking collage of groups deemed incapable of stepping up to the research plate. In 20th century psychological science alone, we have Mary Whiton Caulkins, the brilliant protégé of William James who, by lack of a Y chromosome, was denied her PhD at Harvard (but who later became APA's first female president). It's quite unlikely that APA's founder and first (male) president, G. Stanley Hall, believed that members of ethnic minority groups would be suitable research collaborators, given his disturbing attribution of "adolescent races" who "would be better in mind, body, and morals if they knew no education."

Or perhaps it's believed that by including autistics as research collaborators, objectivity would be foiled. As I hope my previous APS Presidential columns have illustrated, a lot of research on autistics (and research on other groups) is far from objective. As Graham Richards, former historian of the British Psychology Society, has stated, the "general consensus that the scientist detached from the rest of humanity in some realm of pure objectivity has ceased to be a professional ideal, and it was always in any case an unreasonable one."

Besides, I know deaf psychological scientists who study deaf language and culture, blind psychological scientists who study vision, and gay psychological scientists who study sexual orientation. Heck, psychological scientists who study perception and sensation have a long tradition of studying themselves. I underscore Richards' conviction that the study of group differences can only be "socially responsible" if the research is "undertaken by teams drawn from or including members of these groups."

MacArthur "Genius" award recipient Harlan Lane similarly articulated the primary way to make deaf research socially and ethically responsible: "involve deaf people themselves at all levels of the undertaking. Federal agencies such as the Department of Education and the National Institutes of Health, which support most research on deaf people in the United States, should . . . require the projects they sponsor to turn preferentially to the deaf community for advisers and collaborators in research design and implementation, for assistance in data collection and analysis, for guidance in interpretation of results."

NIH already has a mechanism in place for involving autistics through pre- and postdoctoral fellowships that "en-

courage and enable students with disabilities to seek graduate degrees, and thus further the goal of increasing the number of scientists with disabilities who are prepared to pursue careers in biomedical and behavioral research." Aside from graduate training, autistics can ably serve as research collaborators, consultants, and advisers, which doesn't mean being what my 10-year old son and other autistic self-advocates call a "walking zoo exhibit." Autistics deserve a full seat at the main table. As former UN Secretary-General Kofi Annan charged, "no society can claim to be based on justice and equality without persons with disabilities making decisions as full-fledged members."

How to achieve that goal? In her "Open Letter to the Workplace," Jane Meyerding, program coordinator for international studies at the University of Washington, recommends the following: "What autistics, whether we can 'pass' [as non-autistics] or not, are asking for is that other people leave room for us. Us as we are. Even if we 'look autistic' or 'act autistic' or use alternate means of communication. Don't require that we look and sound like you, because some of us can't. Don't judge us on the job (or during the job interview) according to how well we perform the social dance. Give us a chance to show what we can do when who we are is allowed to help shape the world we share with you."

In addition to the ethical imperative of including autistics as true research participants, there are scientific motivations. Nobel Laureate Smith reminds us that "we've lost a lot of the barriers that have to do with skin color and with various other characteristics. But there's still not sufficient recognition of mental diversities. I think it's different kinds of minds, and the recognition that certain mental deficiencies may actually have some selective advantages in terms of activities." Smith gives the example of his ability to "switch out and go into a concentrated mode . . . If I'm writing something, nothing else exists." Who wouldn't want that in a coauthor?

"Perhaps even more importantly," Smith relates, "I don't have any trouble thinking outside the box. And so I have been more open to different ways of looking at a lot of the problems in economics." I value highly autistics' diverse perspective, focused interest, and heightened sense of social justice, along with their occasional jolts of gallows humor. For example, upon reading that the Lifetime Achievement address at the upcoming International Meeting for Autism Research would be titled, "Autism and the Absent Self," Ms. Dawson posted to a discussion board, "so if I attend, I won't really be there? I'll be that empty chair in the back row."



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