

VIEWPOINT

# The elusive essence of autism

BY JON BROCK

28 JANUARY 2014

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Autism research is a new discipline. The condition itself was defined only 70 years ago, and it wasn't until the late 1960s that there was a concentrated effort to address autism experimentally.

We've come a long way since then, but we're still poking around at the edges of the scientific problem. I don't think we've even really figured out what the questions are, let alone come up with good answers.

New sciences take time to mature. All the same, there may be lessons to be learned from older, more established fields of research.

One of the key challenges facing autism research is the heterogeneity within the condition. No two people with autism are alike, and apart from their diagnostic label, they may have little if anything in common.

This heterogeneity is widely acknowledged by researchers. And yet autism research still focuses on the label itself, considering whether *on average*, people with autism are different from people who don't have that diagnostic label.

Underlying this approach is what philosophers would call an "essentialist" view of autism — somehow, beneath all the variation, people with autism share some **essential property** that sets them apart from those without a diagnosis. As SFARI senior scientist **Alan Packer put it in a 2012**

**article:** “Autism is a complex, heterogeneous disorder. But the core phenotype, which can be recognized to some degree in any individual on the autism spectrum, nonetheless suggests that there must be some common underpinnings.”

Attributed to the ancient Greek philosopher Plato, essentialism holds that all members of a category (whether chairs, rabbits or types of people) are mere variations on an ‘ideal’ category member. The lesson from history, however, is that essentialist thinking is a barrier to scientific progress.

The clearest example of this comes from evolutionary biology. Darwin’s breakthrough in understanding evolution required him to stop thinking of members of a species as being variations on a prototype. A species, he realized, is **defined by its variation**, not by its average.

## Statistical limits:

The misleading nature of averages is beautifully illustrated in an essay by evolutionary biologist Stephen Jay Gould titled “The Median Isn’t the Message.” Gould **discusses with remarkable humor** his own diagnosis with a rare and terminal cancer — and the meaning (or otherwise) of life-expectancy statistics.

Having initially discovered that patients with his form of cancer had an average of eight months to live from the time of diagnosis, Gould took inspiration from his scientific and statistical training. He realized that the terrifying statistic obscured a huge amount of variability, that the variation was meaningful and that all indications were that he would live much longer than the average patient. He wrote:

*We still carry the historical baggage of a Platonic heritage that seeks sharp essences and definite boundaries. (Thus we hope to find an unambiguous “beginning of life” or “definition of death,” although nature often comes to us as irreducible continua.) This Platonic heritage, with its emphasis on clear distinctions and separated immutable entities, leads us to view statistical measures of central tendency wrongly, indeed opposite to the appropriate interpretation in our actual world of variation, shadings, and continua. In short, we view means and medians as the hard “realities,” and the variation that permits their calculation as a set of transient and imperfect measurements of this hidden essence ...*

*But all evolutionary biologists know that variation itself is nature’s only irreducible essence. Variation is the hard reality, not a set of imperfect measures for a central tendency. Means and medians are the abstractions.*

The lesson we should take from evolutionary biology is that autism isn’t the average of people with an autism diagnosis. As researchers, we have to take heterogeneity seriously as the object of our investigation, rather than treating it as an excuse for inconsistent results or an inconvenience in our

quest to identify the essence of autism.

As for Gould, he died in 2002, a full 20 years after his diagnosis and of an entirely different cancer. Among his many words of wisdom, the following quote is perhaps most appropriate as we continue trying to get to grips with this thing we call autism: “The most erroneous questions are those we think we know best — and therefore never scrutinize or question.”

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