



For a Radical Change in Autism Research:

Back to the Prototype

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Is research in autism being done with the people that are most knowledgeable about the condition? Should all people being diagnosed with autism today be included in basic research, i.e., research that aims to understand the underlying neurobiological mechanisms of autism? INSAR's (International Society for Autism Research) official journal has devoted, by my initiative, a debate on the question: which "kinds" of autism would allow the progression of scientific knowledge?

In my article, I proposed a radical change of practices on that subject. I argued that the current diagnostic criteria for autism in the DSM-5 are too broad and allow for the inclusion of people whose autism is almost "invisible", to people who are completely dependent on their environment. This encourages a constant increase in the number of autistic people being diagnosed, which has certain consequences on society, but also on autism research. Consequently, the very large population we are now studying in research is increasingly

heterogeneous and includes individuals who are less and less "typically" autistic. This effect can lead to studies finding no difference between the autistic individuals and the general population - thus preventing scientific progress in the understanding of autism. We have therefore made the following proposal for the scientific study of autism: to study in priority the "prototypical" autistic individuals rather than all the people currently included in this category.

What is a prototype?

When we recognize an object, animal, or action, our brain compares it to a prototype, which is a sort of average of the characters of all the exemplars of that category of objects to which we have been exposed. For birds, for example, ostriches will be judged less prototypical of the bird category than, say, sparrows. It has been shown that this prototype is very similar across individuals exposed to "families" of all kinds of birds. Birds closer to the prototype are recognized more quickly

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and with greater certainty, and these are the birds that are most easily distinguished from other categories of the same level.

For the autism diagnosis, an experienced clinician, having been exposed to several hundred autistic individuals of the same age group in diagnostic assessments, will compare the person in front of them to a "prototype" of autism - this is what we call clinical judgment. This prototype does not tell us for sure whether the person autistic or not. It does tell us which individuals are more likely to be autistic, in the eyes of a larger number of

people. There is probably a prototype of autism by age group, very close to what led to Kanner's discovery of autism. In the absence of biological markers that can determine if an individual is autistic or not, clinical judgment remains the only way to identify populations for research. This is not perfect, but it would be better than current instruments that favour fidelity (multiple users of the instrument will reach the same conclusion about whether autism is present), rather than their specificity (distinguishing between autism and other conditions).

What does this "prototype" of autism look like?

What are the characteristics of this prototype? In my experience, it is characterized by :

- 1 onset of signs around 18 months
- 2 Quasi-absence of verbal language until 3-4 years of age
- 3 presence of intense perceptual interests such as close inspection of objects
- 4 normal non-verbal intelligence
 - abilities in some visuo-spatial abilities
 - accelerated recognition of numbers and letters, or other patterns
- 5 apparent indifference to their surroundings (adults and children)
- 6 typical attachment profile with their parents
- 7 refusal to do shared tasks with an adult
- 8 no identified neurologic or genetic comorbidities such as epilepsy for example

My proposal is therefore to do research on groups of people who are as "prototypical" as possible: those who are most quickly recognized, with the greatest certainty, and who would be most readily used for learning about autism. I hypothesize that we would learn more about the mechanisms of autism by studying "very" autistic people.

And what did other researchers think?

The feedback on this proposal has been mixed. While everyone agrees that heterogeneity in research populations is a problem and a barrier to advancing knowledge, the proposed solution is not accepted unanimously! Many people believe that it excludes less prototypical individuals from services, and that the heterogeneity of autism is a "true" trait of autism.

So I have, in response to these criticisms, first clarified that this is a strategy to promote research into the mechanisms of autism - the profound nature of the brain differences between a person with autism and a

person without. This must be absolutely separate from services, which should not be delivered based on diagnosis, but on need.

As for heterogeneity as a characteristic of autism, we fully agree - it is one of the mysteries of autism - that children who are very similar at 3 years old can diverge enormously in adulthood (e.g., one going to college, the other remaining non-verbal). This, to me, is a reason why in research we should focus on individuals who, at the time of diagnosis, are very similar to each other in order to study how they diverge during development, and what makes it possible to predict this. 