Autistic people in research:

decreasing differences?

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Original article: Rødgaard, E. M., Jensen, K., Vergnes, J. N., Soulières, I., & Mottron, L. (2019). Temporal Changes in Effect Sizes of Studies Comparing Individuals With and Without Autism : A Meta-analysis. *JAMA psychiatry*.

The most recent Diagnostic and Statistical Manual of Mental Disorders (DSM-5) places autism in the category of *Autism Spectrum Disorders*. The DSM is a clinical tool, which lists the traits and behaviors associated with different conditions, thereby allowing health professionals to assess a person's mental condition. In the DSM, the term "spectrum" now encompasses several groups of signs, which used to each belong to distinct categories: autism, Asperger's syndrome, and Pervasive Developmental Disorder- Not Otherwise Specified (PDD-NOS).

This notion of a spectrum was not always used to describe autism. The way we define autism has evolved over time. It was first "categorical" under DSM-IV, meaning that the umbrella condition, as well as all its sub-types, were identified as distinct categories. The definition then became more "dimensional" under DSM-5, with autism being defined as a "spectrum", under which similar conditions are grouped on a continuum, which varies depending on the presence and severity of symptoms. By very definition in the DSM-5, autism is heterogeneous. People presenting with different symptoms, each more or less present and more or less severe, may all receive a diagnosis of autism. Although these symptoms have stayed relatively constant throughout different versions of the DSM, this shift in how we describe autism has gradually transformed the way in which we diagnose it, as well as the severity threshold required for a diagnosis.

Along with this evolution in definition, we have also observed over the past few years that the **reported prevalence** of autism has dramatically increased. Since the 1960s, the proportion of autistic people has increased over fiftyfold, from 0.04% to 2.3%. This considerable increase is not found in other neurodevelopmental conditions. If we were to compare this increase to schizophrenia, another heterogeneous condition, we would find that the number of people affected has remained stable over time. So far, the rise in autism diagnoses has been attributed to a better ability to detect it, a widening of diagnostic criteria, or even to a real increase in the actual number of autistic people.

These shifts in definition and prevalence, as well as their consequences, are the main topics addressed by a study published in the prestigious *JAMA Psychiatry* journal in August. The article, a **meta-meta-analysis**, covers data on 27,723 autistic and non-autistic people around the world, who were studied between 1966 and 2019. The study focused on the evolution of our capacity to detect brain and cognitive differences between autistic and non-autistic people.

Autistic people in research: decreasing differences?

Autism research is often focused on differences between autistic and neurotypical people, in order to better understand the mechanisms that underlie this condition. For example, we can compare cognitive abilities or brain size. To detect these possible differences, researchers recruit participants with and without an autism diagnosis. Having measured a particular variable across all participants, the **effect size**, which indicates the magnitude of difference between the groups, will be measured and reported in a scientific article.

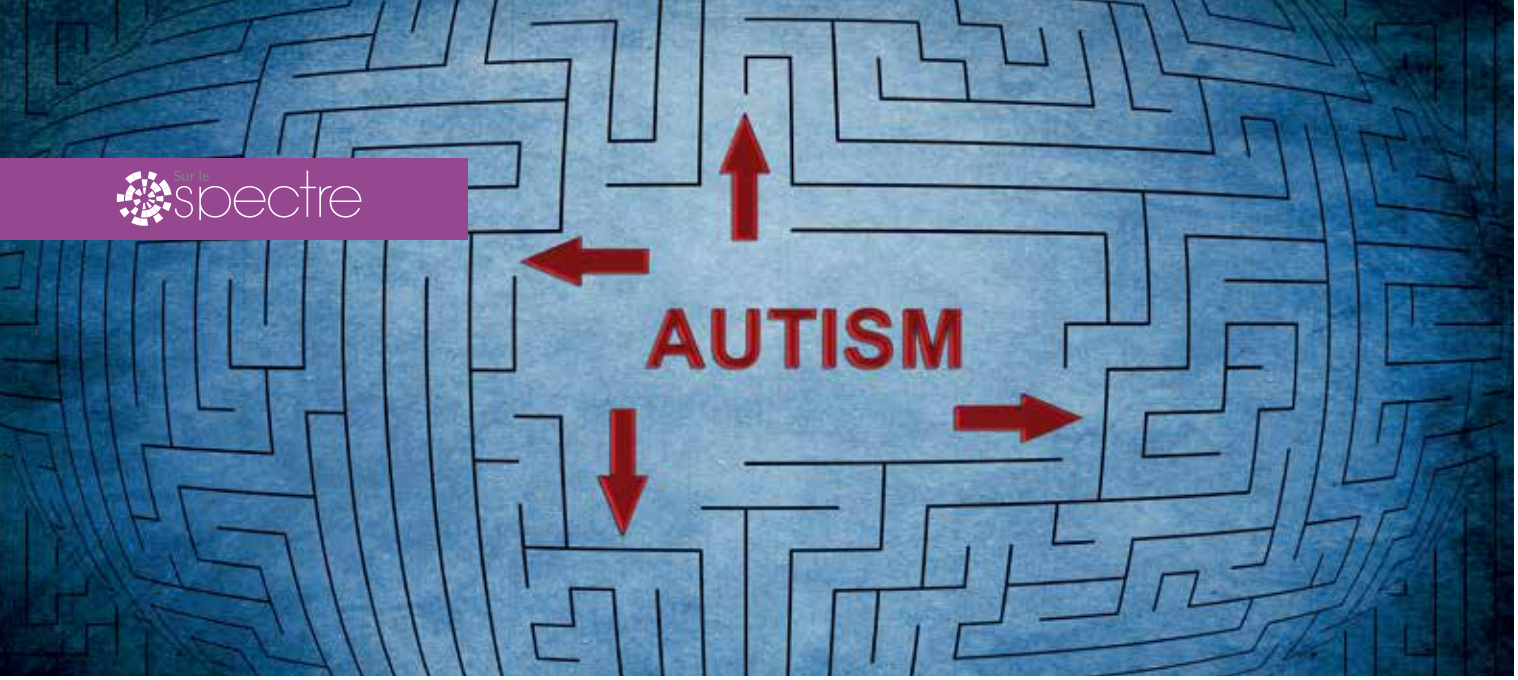
Since autism is increasingly heterogeneous, and the groups being compared are including a growing number of people with very different presentations of autism, the team hypothesized that differences between autistic people and the general population would have gradually

Prévalence

Prevalence refers to the proportion of people affected by a certain illness or condition at a given moment. Prevalence should not be confused with incidence, another important public health measure, which tells us the number of new cases of a particular illness or condition over a given time frame.

Effect size

Effect size is a statistical measure. It allows us to quantify the difference observed between two groups. The higher an effect size, the larger the difference between the groups. For example, for the specific measure of effect size used by the study's authors (which is called Cohen's d), we generally consider that the difference between two groups is large from 0.80. Conversely, the more the effect size approaches 0, the smaller the difference between the groups.



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decreased over time. Based on a set of criteria, eleven meta-analyses were selected, assessing seven psychological and neurological domains in which a certain consensus exists that stable differences can be found in autistic people: emotion recognition, theory of mind (understanding the thoughts and feelings of others and oneself), planning, cognitive flexibility (transitioning between tasks), inhibition, P3b amplitude (neuronal activity indicator) and brain size. The researchers then compared how effect sizes between autistic and non-autistic groups have evolved over 50 years.

The difference between autistic and non-autistic people has significantly decreased (by 45 to 80%) on 5 of the 7 measures of interest. Decreased differences between autistic and neurotypical people were not significant on cognitive flexibility and inhibition, both of which are often altered in attention deficit and hyperactivity disorder (a diagnosis that can now be given in addition to an autism diagnosis). This trend was not observed in studies on people with schizophrenia.

Amongst a few possible explanations for this decreasing ability to detect differences in autism research, changes in diagnostic practices appear to be a probable cause. When current criteria are applied as a checklist, they will capture many people with other diagnoses, or with very minor signs of the condition. Knowing this, how do we set the limit whereby we judge that someone has too few friends, which is a criterion for social deficit in autism? How do we determine whether having few friends is a personal choice, the result of another pathology, or attributable to another cause? Our diagnostic tools cannot answer these types of questions, and it is via these very mechanisms that a person with very few autistic symptoms can end up with a diagnosis.

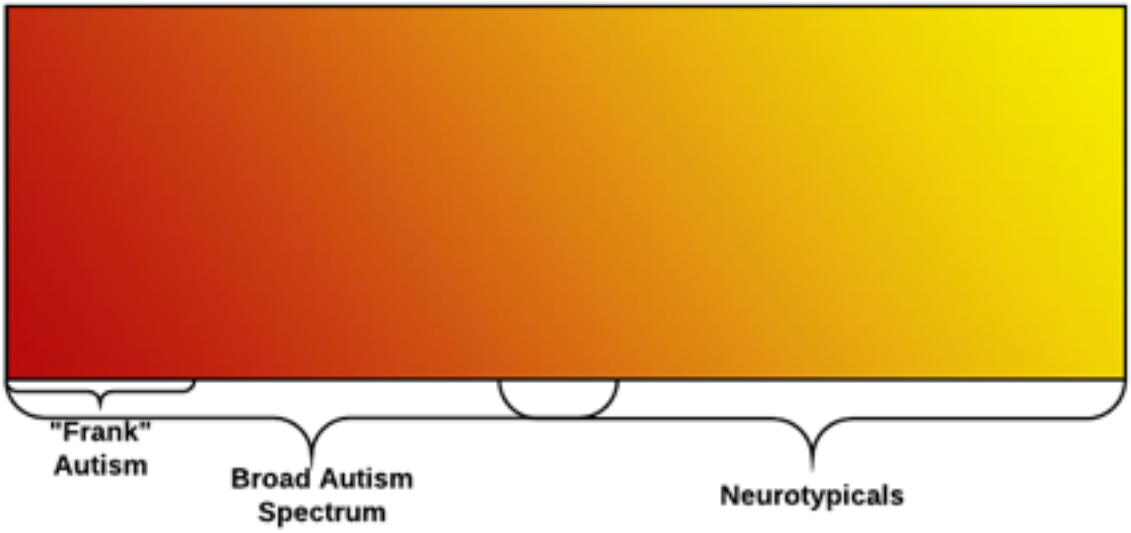

Diagram representing the "loss of signal" in autism. When comparing the red ("frank" autism, that is autistics for whom the diagnostic is really clear) to the yellow (neurotypicals) we find clear differences between the groups. However, when we include a lot of people belonging to the orange category (broad autism spectrum) we find fewer differences with the yellow (neurotypical).

What this study indicates, and what it does not.

This important study, first-authored by an autistic researcher, demonstrates an apparently irreversible tendency to define autism in a way which prevents us from understanding how it works, and thus what causes it. Despite extensive international media coverage, the significance of this study has often been misunderstood. It can explain that no great discoveries have been made in autism over the past fifteen years : how can we discover the cause of a difference between two groups of people if these groups have become… almost identical!?

However, this study does *not* indicate that people with minor signs of autism have less of a need for services, or worse, that they should not receive any. On the contrary, it advocates for care and services on the basis of need, not diagnosis. Otherwise, a vicious circle appears in which diagnoses are given more and more liberally and in a way that is less and less relevant to the needs of the person.

The study's authors do not question that certain people present with signs with are less present, identifiable or severe that those at the furthest extremity of the autism spectrum. The most important conclusions from this study are for research, where it may be unwise to include as many autistic participants as possible, if it lowers the homogeneity and representativity of the group by including persons less and less typically autistic. It would probably be better to focus on smaller populations with more typical presentations, or on large samples if clear and valid information on the autistic subgroups present is available. By including ever increasing numbers of people in research, all with very different presentations of autism, we "lose the signal". It thus becomes harder to find differences between autistic and non-autistic individuals.

Another point is important to clarify, because it has been largely misunderstood. There is *no* argument being made that autistic people of high intelligence or with Asperger's syndrome should be excluded from research. One can indeed be "very autistic" and "very intelligent". There is also no argument being made to exclude people who are relatively well adapted within mainstream society: one can be "very autistic" and in certain cases very well adapted. The point is rather that research must be undertaken on people with diagnoses that are clear and unmistakable, and that do not overlap with other conditions that could be mistaken for autism.

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Participants wanted

Differential diagnosis in autistic women

We want to hear from you!

Do you diagnose autism in adults,
or know someone who does?
This study is led by **Dr. Laurent Mottron**, Université de Montréal, and **Rivière-des-Prairies Hospital**, and will involve a phone interview on your experiences diagnosing autism in adult women with no intellectual disability.

Please contact

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This project has been approved by the Research Ethics Board of the CIUSSS du Nord de l'Ile de Montréal.