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Autism Explained in **10** Numbers

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Over several decades, our understanding of autism has followed certain trends. At times, evidence accumulated against these trends and researchers reversed their position on the topic – almost like the swing of a pendulum. For the general population and for professionals, such contradictory messages can be a source of confusion. In this article, we will tackle 10 fundamental principles of autism. For each principle, we will explain which ideas prevailed when autism was first studied, then how this trend came to be reversed – the swing of the pendulum, and finally our current understanding of the topic.

1 **1/200 people around the world are autistic**
Where did we start? Autism cases have steadily increased since the 1940s, when the first autism cases were identified. In the United States for example, official estimates were of 4 cases per 10,000 people in the 1970s. **The pendulum swings:** Autism monitoring agencies in the US recently estimated that prevalence was higher than 1/50. Whilst Quebec did not announce such high prevalence, it did find an overall prevalence higher than 1%, reaching nearly 2% in certain regions such as Montréal. **Current understanding:** This constant increase may be artificial. Indeed, the

number of autism cases is calculated based on the number of pupils in specialised classes, where a diagnosis is not independently verified. Studies with rigorous methods question whether autism has truly increased over the past 20 years, instead reporting that around one in 200 people around the world are autistic.

2 **Fewer than 10% of autistic people have an identifiable genetic anomaly**
Where did we start? We have known for over 50 years that autism involves a genetic component. This is due to increased risk for autism within families already having an autistic child, and greater concordance of autism in identical twins than in non-identical twins. **The pendulum swings:** During the Golden Age of autism genetics research, some scientists affirmed that autism was genetically identifiable in 30 to 40% of cases. **Current understanding:** Genetic pathologies can be identified in fewer than one in ten autistic people. Referred to as “syndromic” cases, these autistic people have distinct presentations when compared to autistic people with no identified cause, and almost always have an intellectual disability.



3 Autism is 3 times more prevalent in boys than in girls

Where did we start? Historically, 4 times more boys than girls were diagnosed autistic. **The pendulum swings:** This ratio started to be challenged around 15 years ago, with the scientific community suggesting that many autistic girls were not being diagnosed and were flying under the radar. Indeed, diagnostic criteria may centre male presentations of autism, and girls may “camouflage” their symptoms. Some even affirmed that, were we able to assess girls as thoroughly as boys, we would find as many autistic girls as boys. **Current understanding:** Despite efforts to identify more autistic girls, recent studies report around 3 autistic boys for every girl – ultimately fairly close to the initial ratio reported half a century ago.

4 1/8 of autistic children’s siblings are also autistic

Where did we start? At the very beginning of autism research, we did not know that autism was a genetic condition. Parents presenting with psychological differences were thought to have caused their child’s autism. This was Bruno Bettelheim’s notorious “refrigerator mothers” theory. **The pendulum swings:** When evidence accumulated to suggest a genetic cause of autism, scientists began to search for the “autism gene” and promised this would be a quick process that would explain everything. **Current understanding:** Many genes are involved in autism, interacting with each other and with as

of yet unidentified environmental factors to cause autism. What this means is that autism is not a genetic condition in the same way as hemophilia, where it is possible to reliably calculate the risk of a child having the same condition as their parents. Moreover, having an autistic child increases risk of having another autistic child twentyfold with each new birth. However, this does not predict symptom severity of the second child if he or she is autistic, nor does it predict intellectual functioning. Parental characteristics therefore do not cause autism in their child, but rather reflect the same genetic mechanisms.

5 The proportion of autistic people presenting with an intellectual disability depends on how and with whom we measure it

Where did we start? For many decades, it was thought that autism was associated with an intellectual disability for around 3 in 4 autistic people. **The pendulum swings:** As the autism spectrum came to include more people presenting with fewer differences when compared to the general population, this number decreased to around 1 in 10 for the entire spectrum. Our research group’s work contributed to re-examining how we assess intelligence in autism and demonstrated that we tend to underestimate autistic people’s intelligence by measuring their capacity to complete a test rather than their actual reasoning skills. **Current understanding:** Most autistic people have some

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form of intellectual limitations. However, when intelligence is correctly assessed in non-syndromic autistic people, the proportion of people presenting with an intellectual disability is quite close to that found in the general population. Thus, providing an estimate for the entire spectrum would be misguided.

6 10% of school-aged autistic children will remain non-verbal

Where did we start? Several decades ago, it was not only thought that 75% of autistic people were intellectually disabled, but also that a majority would never develop speech. **The pendulum swings:** As more people were included in the autism spectrum, the same phenomenon occurred as with intellectual functioning, meaning that many autistic people did not present with any language problems and thus this proportion significantly decreased at the turn of the century. **Current understanding:** Speech can develop much later than was originally thought. A vast majority of autistic people with no intellectual disability will ultimately develop speech, but a small proportion (around 1 in 10) will not no matter what. The prognosis for “syndromic” autism is not as good, but as always difficult to predict.

7 Between 1 in 10 and 1 in 2 autistic people have a mental health condition, depending on the nature of the condition

Where did we start? For many years, autism was defined in its “pure” form in children, meaning no other disorders could be associated. **The pendulum swings:** When scientists began to search for psychiatric conditions that could be “comorbid” for autistic adults, researchers posited that a majority (75%) also presented with a mental health condition. **Current understanding:** We now make a distinction between psychiatric conditions (anxiety, depression, OCD, etc.) and what we call “aggravating” symptoms. The latter are symptoms included in clinical presentations of autism, but which are present in higher levels in certain individuals when compared to other autistic people. For examples, clinicians will distinguish social difficulties found in all autistic people from social anxiety disorder as well as autism. In this case, observable symptoms must be greater than what could be expected given autism.

8 60% of autistic people present with domain-specific skills

Where did we start? Autism was first defined as an entirely disabling condition, although memory skills in some autistic people were described early on. **The pendulum swings:** In the 1970s and 80s, a study reported that 10% of autistic people presented

with exceptional talents. Films such as Rain Man, based on real but isolated cases, contributed to this idea that all autistic people were gifted in some way.

Current understanding: It can be said of most autistic people that they present with increased capacity in one domain when compared to another, without necessarily performing higher than the general population. Autistic talents not found in the general population do exist but remain relatively rare. For example, calendar calculation abilities (finding the day of a specific date) are almost exclusively found in autistic populations but have only been described in a few hundred autistic people around the world.

9 Fewer than 1 in 2 autistic adults live independently

Where did we start? Longitudinal studies of early cohorts of autistic adults depicted quite a dark picture of their future. It was considered almost impossible for autistic adults to live independently.

The pendulum swings: We then observed a complete reversal of this belief, when the trend morphed into pushing computer programming jobs on all autistic people, as this appeared to be a strength present in some of them. A lot of pressure was exerted to promote the development of social skills, as it was thought that all autistic adults could then be integrated into typical professional settings and living arrangements.

Current understanding: Although much progress has been made to promote equal rights and access to employment for autistic people around the world, most adults still encounter specific challenges linked to professional opportunities and discrimination. Some type of support will often be required throughout the lifespan, and this support is unfortunately rare. Services remain largely monopolised by support for autistic children and their families. Much work remains in this area.

10 50% of referrals to Hopital Rivièredes-Prairies' child psychiatry services are to assess for autism!

Where did we start? Autism was underdiagnosed in Quebec and the rest of the world until the turn of the century. This situation was even more dire for adults and women. **The pendulum swings:** The other extreme is now true – autism is overdiagnosed and many people receiving an autism diagnosis actually present with very few signs of autism, or symptoms suggesting a different condition.

Current understanding: We must return to a more balanced approach. This will, however, require a rethinking of how we organise service access and delivery, to ensure that they are provided based on personal need and not diagnostic labels.

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