



Autism Explained in 10 Numbers



10 characteristics of the autistic brain.





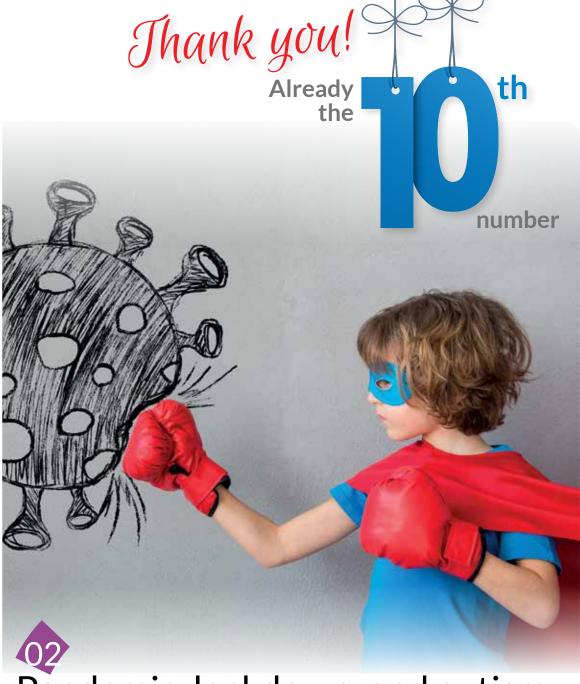
Autism and factors risk



Autism, childhood to adulthood



Making use of autistic children's special interests and cognitive strengths



Pandemic, lockdown, and autism: from distress to solutions





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CHAIRE DE RECHERCHE MARCEL ET ROLANDE GOSSELIN
EN NEUROSCIENCES COGNITIVES FONDAMENTALES
ET APPLIQUÉES DU SPECTRE AUTISTIQUE





Autism Explained in 10 Numbers





10 characteristics of the autistic brain.





Risk factors: Baby steps towards understanding the development of autism.





Autism symptomatology and intellectual functioning: what happens from childhood to adulthood?





Making use of autistic children's special interests and cognitive strengths





Official magazine of the The Montreal Cognitive Neuroscience Autism Research Group

The Montreal Cognitive Neuroscience Autism Research Group focuses on brain function, auditory and visual perception, exceptional skills and interventions in autism.

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## Many thanks!

This fall, we give you a very special issue of Sur le Spectre. Indeed, this is our tenth issue! We are so very proud of this project which has continued to grow and thrive. This is, of course, made possible thanks to renewed support from our sponsors, the Petits Trésors Foundation, Marcel and Rolande Gosselin Fundamental and Applied Cognitive Neuroscience of Autism Research Chair at the Université de Montréal, the Réseau National d'Expertise en TSA (RNETSA), and also the support of the CIUSSS-NIM Research Department. This project would also not have seen the light of day without the students, clinicians and researchers who volunteer to write and review articles, and, of course, without you, our faithful readers!

Our mailing list now has over 3,000 subscribers, which will allow us to expand the project even further in the coming months. With the support of the CIUSSS-NIM Research center, we were able to apply for and obtain a DIALOGUE grant from the Fonds de Recherche du Québec en Santé. This grant will be used to set up a YouTube channel and create a video version of a Sur le Spectre article in collaboration with Spectrum Productions. We hope to then obtain continued funding to produce video versions of our articles and keep making autism research more accessible.

In this issue, two special articles highlight our 10th issue: Autism Explained in 10 Numbers, and 10 characteristics of the Autistic Brain. You will also find an article presenting very recent data on the impact of COVID-19 on autistic people and their families, an article summarising a literature review on risk factors for autism, and finally an article summarising a longitudinal study conducted over 10 years.

Happy reading!



Valérie Courchesne Ph.D.

Chief editor

Our mailing list now has over 3,000 subscribers, which will allow us to expand the project even further in the coming months.









## Pandemic, lockdown, and autism:

#### from distress to solutions

## By CLAUDINE JACQUES, ISABELLE SOULIÈRES, GENEVIÈVE SAULNIER, GHITZA THERMIDOR and KATIA ELKOUBY

The COVID-19 pandemic has an important impact on the entire world and has significantly changed the lives of many families. Just like everyone else, autistic children and their families lived through the trials of the lockdown and physical distancing. However, no data currently exists on the experiences of autistic¹ children and their families during this situation, or on the resources helpful to their well-being.

As researchers and clinicians, we were interested in the needs of autistic children (aged 2 to 18) and their families during this crisis, in order to propose recommendations that would guide support services. We therefore surveyed parents and children themselves.

To date, 90 parents have taken our survey, largely through an online questionnaire. 53 autistic children (4 to 18 years old) have also provided their opinion on the current situation. In this article, we would like to summarise initial results.

**73%** of parents declared not being more concerned than usual about their child's development.

How to explain this results? Is this due to the fact that:

Only further analyses will allow us to answer these questions.

Two different parental profiles emerge from the data. For some parents, the situation has **not been problematic**:

The lockdown was absolutely not a difficult period for him nor for us. In fact, the ability to dedicate himself to his passion in an independent way was very positive for all of us. — Parent of a 16-year-old autistic boy.

For others, the situation has **caused significant distress**:

We felt left to our own devices, no one stepped in to help us during this time. It is the worst thing my boy has lived through, and us as well as his parents. — Parent of a 15-year-old autistic boy.

Two different parental profiles emerge from the data. For some parents, the situation has not been problematic



<sup>1</sup> Autistic refers to a diagnosis of an Autism Spectrum Disorder (according to DSM-5), or Asperger's Syndrome, autism, Pervasive Developtmental Disorder-not otherwise specified (according to DSM-IV-TR)...

#### **Parents**

83%

Reported a high level of knowledge about autism

#### 79%

reported not feeling depressed in the wake of stressful situations

#### 52%

do not perceive the pandemic as a great source of stress, but rather report seeing it as an opportunity to make the most of quality time



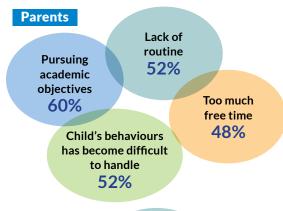


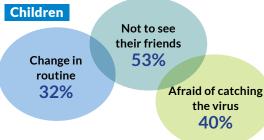


Ensure that information and guidelines issued by authorities are fair and coherent.

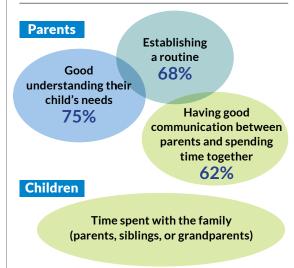
#### Which daily challenges were reported?

Many factors were identified as having adverse effects on daily life.

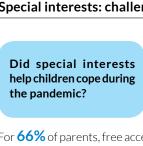




#### Which factors facilitated adaptation?



#### Special interests: challenge or solution?

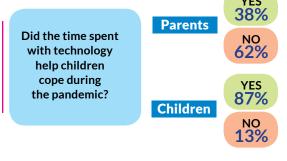




YES **50%** 

For 66% of parents, free access to technology was the first accommodation made to preserve family balance.

**Parents** 



In sum, special interests, particularly for technology (computer, tablet, video games, cell phone) occupied a large space in autistic children's daily lives during the lockdown. The role these interests play must therefore be better understood by parents in order to integrate them appropriately into daily life.

#### How can we better support children and their families? Some starting points.

Parents identified several measures that organisations could implement to increase their well-being.

#### For the GOVERNMENT

Ensure that information and guidelines issued by authorities are fair and coherent. This information is important, as parents indicated that 51% of children obtained information about COVID-19 through the media:

> A clear and consistent message from the Ministry of Education would have been necessary. After having sent the kids off wishing them a great summer and repeating that schoolwork was optional and would not count towards their final report card, it didn't make sense to finally mandate school work and say it would possibly be graded. My son mostly retained the first and second message. It was very hard to get him to do more than the bare minimum. - Parent of an autistic 16-year-old boy

Offer respite and financial compensation:

The government could have helped by offering money to go towards some respite. I was left to fend for myself which caused a lot of anxiety until I experienced parental burnout. -Parent of an 11-year-old autistic girl.

#### For HEALTH AND SOCIAL SERVICES

 Maintain specialised services and facilitate access to autism specialists:

We would have liked for services supporting families with an autistic child to be considered as essential services. — Parent of a 6-year-old autistic boy.

#### For EDUCATIONAL SERVICES

Accelerate the setup of distance learning and ensure follow ups with school staff so that children can follow a routine and familiarise themselves with adapted teaching tools:

Call more frequently to check in on the needs of the child and their family. — Parent of an 18-year-old autistic girl.

 Offer opportunities for children to socialise, to combat social isolation:

Organise groups in CEGEP of students who have an autism diagnosis or other similar condition. It would have been helpful for him to know that he was not the only one dealing with anxiety. — Parent of an 18-year-old autistic boy. It would be nice if he could have a spot at day-care and could see other children. — Parent of a 4-year-old autistic boy.

#### For PROFESSIONAL ENVIRONMENTS

 Build awareness amongst employers to allow better understanding and flexibility in terms of managing work:

Take into account the situations of families living with an autistic child and allow for some exceptions. — Parent of an 8-year-old autistic child.

In sum, these results suggest that lockdown was experienced in very heterogeneous ways by parents as well as children. Although parents attempted to deploy numerous strategies to facilitate daily adaptation, these preliminary results reveal the necessity to put in place more supportive measures that promote family well-being. Parents highlighted that adapted measures which considered autistic children's needs and particularities were crucial to put in place. Autistic children indicated the need to maintain contact with their peers.

A huge thank you to all the parents who took the time to participate online or by interview, and children who shared their lived experience with us. We would also like to thank the research assistants for their incredible work: Katarina Sotelo, Jade Desrosiers, Agnès Ethier and Chloé Belley.

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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

## Autism Explained in

#### By LAURENT MOTTRON and VALÉRIE COURCHESNE

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.

#### 1/200 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 Montérégie. 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.

**Numbers** 

## 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.



## 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.

#### 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.

## 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

#### Main references:

- 1- Elsabbagh M, Divan G, Koh YJ, Kim YS, Kauchali S, Marcín C, Montiel-Nava C, Patel V, Paula CS, Wang C, Yasamy MT, Fombonne E. Global prevalence of autism and other pervasive developmental disorders. Autism Res. 2012 Jun;5(3):160-79. doi: 10.1002/aur.239. Epub 2012 Apr 11. PMID: 22495912; PMCID: PMC3763210.
- 2- 2 Vicari S, Napoli E, Cordeddu V, Menghini D, Alesi V, Loddo S, Novelli A, Tartaglia M. Copy number variants in autism spectrum disorders. Prog Neuropsychopharmacol Biol Psychiatry. 2019 Jun 8;92:421-427. doi: 10.1016/j. pnpbp.2019.02.012. Epub 2019 Feb 20. PMID: 30797015.
- 3- Loomes R, Hull L, Mandy WPL. What Is the Male-to-Female Ratio in Autism Spectrum Disorder? A Systematic Review and Meta-Analysis. J Am Acad Child Adolesc Psychiatry. 2017 Jun;56(6):466-474. doi: 10.1016/j.jaac.2017.03.013. Epub 2017 Apr 5. PMID: 28545751.
- 4- Sandin S, Lichtenstein P, Kuja-Halkola R, Larsson H, Hultman CM, Reichenberg A. The familial risk of autism. JAMA. 2014 May 7;311(17):1770-7. doi: 10.1001/jama.2014.4144. PMID: 24794370; PMCID: PMC4381277.



5- Courchesne V, Meilleur AA, Poulin-Lord MP, Dawson M, Soulières I. Autistic children at risk of being underestimated: school-based pilot study of a strength-informed assessment. Mol Autism. 2015 Mar 6;6:12. doi:10.1186/s13229-015-0006-

3. PMID: 25774281; PMCID:

PMC4359559.

6- Mouga S, Correia BR, Café C, Duque F, Oliveira G. Language Predictors in Autism Spectrum Disorder: Insights from Neurodevelopmental Profile in a Longitudinal Perspective. J Abnorm Child Psychol. 2020 Jan;48(1):149-161. doi: 10.1007/s10802-019-00578-7. PMID: 31410701.

- 7- Hossain MM, Khan N, Sultana A, Ma P, McKyer ELJ, Ahmed HU, Purohit N. Prevalence of comorbid psychiatric disorders among people with autism spectrum disorder: An umbrella review of systematic reviews and meta-analyses. Psychiatry Res. 2020 May;287:112922. doi:10.1016/j.psychres.2020.112922. Epub 2020 Mar 18. PMID: 32203749.
- 8- Meilleur AA, Jelenic P, Mottron L. Prevalence of clinically and empirically defined talents and strengths in autism. J Autism Dev Disord. 2015 May;45(5):1354-67. doi: 10.1007/s10803-014-2296-2. PMID: 25374134; PMCID: PMC45444492.
- 9- Magiati I, Tay XW, Howlin P. Cognitive, language, social and behavioural outcomes in adults with autism spectrum disorders: a systematic review of longitudinal follow-up studies in adulthood. Clin Psychol Rev. 2014 Feb;34(1):73-86. doi: 10.1016/j.cpr.2013.11.002. Epub 2013 Dec 4. PMID: 24424351.

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.

### 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.

## 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.

## 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.

## Fewer than $\boldsymbol{1}$ in $\boldsymbol{2}$ 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.

### 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.

# characteristics of the autistic brain.

#### By ÉLISE BROCHU-BARBEAU

We list here -in no particular order- 10 widely replicated differences between the brains of autistic people as a group, and typically developing individuals. These differences may not be found in all people, as autistic or not, individual variation exists. For example, people with speech onset delays do not present with the same brain signature as those without, and male/female cerebral differences may also exist.

- Over-functioning of visual brain areas. Autistic individuals recruit the brain areas associated with visual processing and perception to a greater extent than non-autistics, even for complex, verbal tasks that require language in non-autistic people.
- Altered long-range brain connectivity. Although it depends on the brain area, we often observe decreased communication between brain regions, especially between the frontal and more posterior brain regions. This "diminished long-distance connectivity" indicates that brain regions may function more autonomously in autistic people.
- Local over-connectivity. Conversely, communication is enhanced within functional brain regions, and sometimes between two closely connected regions. This is the case between visual brain areas and other perceptive regions, which could explain high rates of "synesthesia" in autism such as associating a musical note and a color.
- Differences in cellular size and organisation. Cell size and organisation differ in certain areas of the autistic brain, which incidentally contains a greater quantity of smaller brain cells (or neurons). This may influence the distance across which the neurons can communicate.
- A larger brain. Around one third of autistic individuals have a larger head and brain size compared to the average non-autistic population of the same

height. These individuals are generally of typical intelligence.

- Reduced corpus callosum. This brain structure allows for communication between the left and right hemispheres of the brain. At least some parts or the corpus callosum are thinner in autistic people which may affect the speed and efficiency of the connection between the two hemispheres.
- Less lateralized brain structure and function. Several brain functions are lateralized. For example, the left hemisphere is more specialised in language processing than the right hemisphere. Conversely the right hemisphere is better at processing music and faces. In the autistic brain these functions seem to be more equivalently processed in the two hemispheres. In line with these findings, there are more left-handed and ambidextrous individuals in the autistic that the non-autistic population.
- Different growth and development trajectory. In autistic individuals, there is an early brain overgrowth, which normalizes after a few years, and is plausibly linked with differences in the way the brain organizes its structure and connections during development.
- More interindividual variability. In the non-autistic brain, some regions are dedicated to specific functions. For instance, faces are specifically processed in a brain region called "fusiform gyrus". This is also true for autistic people, but to a lesser extent: for example, this face processing region is more variable from one individual to another.
- Organised differently. Overall, the autistic brain is organised differently, more efficient than the non-autistic brain in some cognitive aspects, less efficient for others.

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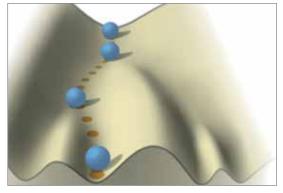
They also paint a more complex picture, pointing out that many of these genes are also linked to other developmental conditions and people without a diagnosis, and may impact individuals differently.

## Risk factors:

Baby steps towards understanding the development of autism.

#### By SCOTT HUBERTY

In a previous issue of Sur Le Spectre, a geneticist explained that hundreds of genes appear to be associated with autism. They also paint a more complex picture, pointing out that many of these genes are also linked to other developmental conditions and people without a diagnosis, and may impact individuals differently. This article takes the discussion a step forward discussing the array of biological and non-biological factors leading to autism diagnosis and other behavioural outcomes.



Original Reference: https://plos.figshare.com/articles/figure/\_Waddington\_s\_8220\_Epigenetic\_Lands-cape\_8221\_/620879

It can be useful to conceptualize this relationship between factors that increase the likelihood of developing autism

or a developmental condition (risk factors), and a person's actual developmental outcomes, as a landscape: In the picture below, the ball at the top of the hill would represent an infant, and the hill below represents different potential developmental journeys. The presence of one or more risk factors that increase autistic likelihood can nudge an infant towards a certain developmental path. The start of each path represents early brain development, and further down the hill represents behavioural development. You may have noticed that it appears easier to switch between paths when higher up the hill; this reflects that earlier in life there is greater brain plasticity (the ability to amend connections between neurons).

In autism, researchers now have identified some risk factors that increase the likelihood of autism. The table below (Figure 2) presents some of the many factors that are recognized in the scientific community as being associated with autism (Part A). These factors are usually present from birth and are thought to influence the development of brain networks by shaping how neurons form connections with one another (Part B). This different brain development can in turn influence behavioural outcomes in domains either specific to autism (i.e. social communication) or more broadly (such as language development) (Part C).

However, these risk factors (part A), despite being consistently associated with higher likelihood of autism,

are also seen in other developmental conditions. That means they are not unique to autism, and more research needs to be done to better understand how two

individuals with the same risk factors (both having the same genetic mutation for example) can diverge in two distinct developmental journeys.



Figure adapted from the original paper

Because changes in the brain typically precede changes in behaviour, studying early brain development in infants can help us to better understand how the aforementioned risk factors determine which developmental journey a child might follow. Most studies aim to do this by following infants who have an older autistic sibling, because family history of autism is a factor that increases the risk of developing autism.

These studies often record EEG (a non-invasive tool that measures the activity of brain networks, sometimes referred to as brain waves!) with the infants. By recording EEG at multiple time points throughout early development,

researchers can gain a clearer picture of how the brain develops in children, and whether certain risk factors influence this brain development. A team led by Dr. Mayada Elsabbagh at McGill's is leading such a study that has collected EEG's from over 400 infants from both North America and Europe multiple times throughout the first years of life. By studying the relationship between risk factors of autism, brain development, and developmental outcomes, Dr. Elsabbagh and her team hope to help us better understand what determines the developmental journey a child will undergo, particularly in children at risk for autism.

#### **Original Reference:**

Elsabbagh, M. (2020). Linking risk factors and outcomes in autism spectrum disorder: Is there evidence for resilience? British Medical Journal (Clinical Research Ed.), 368, l6880. https://doi.org/10.1136/bmj.l6880



## RNETSA ANNUAL EVENT

BEYOND KNOWLEDGE:
TARGET INTERVENTIONS
FOR AUTISM AND ITS
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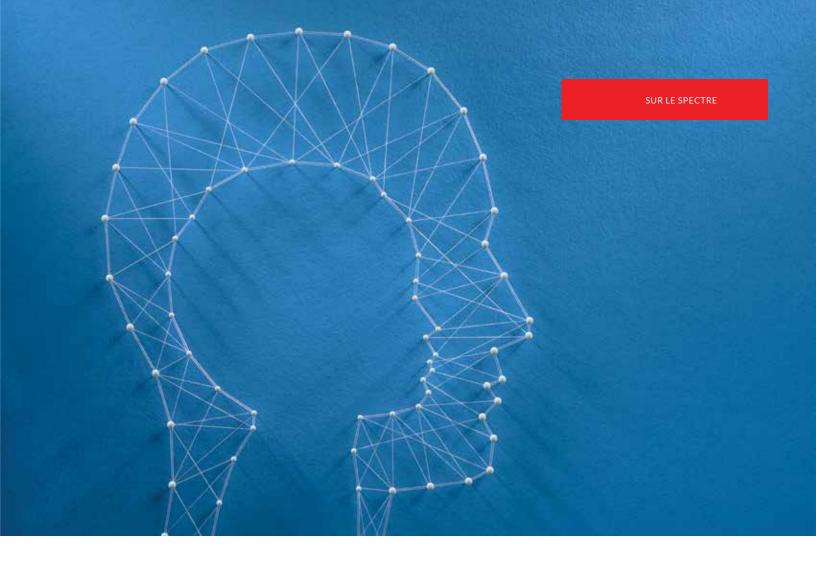






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## Autism symptomatology and intellectual functioning:

what happens from childhood to adulthood?

By VICKY CARON, JANIE DEGRÉ-PELLETIER and ANNE-MARIE NADER

What does the future hold for my child? This question is often a source of worry for many parents of autistic children. Though autism is a neurodevelopmental condition present throughout one's life, autism symptoms such as social difficulties, as well as cognitive abilities and adaptive functioning can change over time with individual variation. Until recently, data from studies looking at the evolution of young autistic children into adulthood was very heterogenous. There was also no consensus in the literature on factors influencing developmental trajectories in autism, other than language and IQ, both of which were considered favourable to development. Few predictive factors had been identified, and family and social factors were rarely considered as possible predictors of child development.

In order to address these gaps in the scientific literature, Simonoff and her team documented the evolution from childhood to adulthood of 158 people having received an early diagnosis of autism, Asperger's Syndrome, Pervasive Developmental Disorder-Not Otherwise Specified, or atypical autism according to ICD-10¹. This is considered a first in the field, where no cohort this large had ever been studied for this long. Participants were evaluated at ages 12, 16 and 23, and completed a variety of measures. Intellectual functioning was assessed with the Wechsler IQ scales and autism symptoms were assessed with the Social Responsiveness Scale (SRS). The research team also explored the role of different predictive variables, including 1) childhood characteristics (autism symptoms

Few predictive factors had been identified, and family and social factors were rarely considered as possible predictors of child development.

<sup>&</sup>lt;sup>1</sup> DSM equivalent used in Europe





Thus, autistic children having experienced language regression followed a different developmental trajectory than children who had not experienced language regression, and this difference persisted into adolescence and adulthood.

#### Original article:

Simonoff, E., Kent, R., Stringer, D., Lord, C., Briskman, J., Lukito, S., ... & Baird, G. (2019). Trajectories in symptoms of autism and cognitive ability in autism from childhood to adult life: Findings from a longitudinal epidemiological cohort. Journal of the American Academy of Child & Adolescent Psychiatry.

in infancy, language development, presence of language regression); 2) parent characteristics (mother's affective symptoms, parent education) and 3) other life characteristics (socio-economic status of their neighbourhood, type of school attended, etc.).

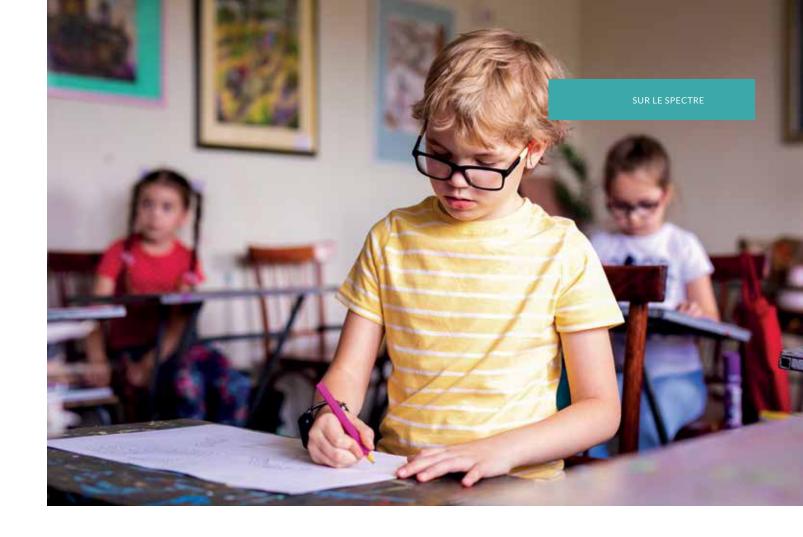
Results showed that when the group was considered as a whole, **mean IQ increased** between the ages of 12 and 23 years old for autistic individuals, whilst no such variation is expected in the general population since IQ scales are normed by age. The authors offered two hypotheses to explain this IQ increase: 1) cognitive development may be continuous throughout adolescence/young adulthood in autistic people, contrary to typically developing individuals where we observe stable IQ, and 2) autistic children may be more able to participate in formal assessments as they get older, notably for tasks evaluating language, allowing them to showcase their full capacities. Autistic symptoms remained stable through time when considering the group as a whole.

In terms of the role of certain variables, such as childhood, parental and life characteristics on the evolution of intellectual functioning (IQ), results showed that **lower language levels** in childhood were associated with **lower IQ** between 12 and 23 years old. Furthermore, having experienced **language regression** at a young age was associated with an **IQ increase** between 12 and 23 years old. Thus, autistic children having experienced language regression followed a different developmental trajectory than children who had not experienced language regression, and this difference persisted into adolescence and adulthood.

When researchers observed the evolution of autism symptomatology, they found that higher levels of **sociocommunicative difficulties** at a young age predicted more **autism symptoms** at age 12. Higher

levels of sociocommunicative difficulties and symptoms of mental health problems were also associated with higher levels of autism symptomatology at age 23. Although overall levels of autism symptoms remained stable over time, youths having attended a specialised school presented with increasing autistic symptoms between 12 and 23 years old, contrary to children who attended a regular school, who showed decreasing symptoms from childhood to adulthood. It is however important to note that the authors also found that children with lower IQs were more likely to attend specialised schools no matter their age. It is therefore not possible to determine whether changes in autism symptoms are best explained by the type of school attended or baseline characteristics of the child. Lastly, neither maternal mental health, parental education nor socio-economic status were associated with the trajectory of autistic symptoms or the evolution of the child's cognitive profile.

In conclusion, this study was one of the first populational level studies to document different trajectories of cognitive development and autistic symptoms from childhood to adulthood. Results suggest that cognitive functioning tends to improve with age, whilst autism symptoms remain stable. The authors also demonstrated that certain factors may impact development in autistic people, such as language levels in childhood and the type of school children or adolescents attend. Although this study was limited in some ways, such as a lack of measures before age 12 or too few female participants to allow for comparisons between girls and boys, these results nonetheless demonstrate that different developmental trajectories exist across the autism spectrum, influenced by both individual and environmental factors.



# Making use of autistic children's special interests and cognitive strengths

#### Par AUDREY ST-LAURENT

Autistic people present with intense interests which we will refer to as special interests. It is increasingly suggested that special interests be used with autistic children for academic learning, and that they may be a useful way to keep autistic students motivated. Numerous strengths and capacities have been reported in autism research (e.g. visual/auditory memory, special abilities in reading/mathematics, detecting irregularities) which could also be used to foster learning. Though often recommended to both parents and teachers, these promising avenues can be tricky to transfer into action!

Autistic students have specific pedagogical and educational needs in line with their particularities, and educators often report feeling unequipped to address these needs<sup>1</sup>. As psychoeducation researchers, we interact with both educational and social services. In doing so, we noticed that the same question often arose: How

do we use autistic pupils' strengths and interests to optimise their potential? We began our project with this question in mind. Indeed, it has been consistently identified by both researchers and educators that a lack of knowledge about autism, little training on available interventions and the stress experienced when welcoming an autistic pupil in the classroom for the first time can all negatively impact academic achievement in autistic students<sup>2</sup>.

We started by examining the scientific literature on cognitive processes in autism, as well as commonly reported preferred interests and ways to effectively use these interests and strengths in educational settings. This allowed us to suggest intervention strategies aimed at promoting school inclusion, achievement, motivation, optimising potential and ultimately maximizing quality of life at school for autistic children. We created an

In practice, the questionnaire is filled out by someone close to the child (ideally the children themselves).

- <sup>1</sup> Gunn, K. C. M., & Delafield-Butt, J. T. (2016). Teaching children with autism spectrum disorder with restricted interests: A review of evidence for best practice. Review of Educational Research, 86(2), 408-430. doi:10.3102/0034654315604027
- <sup>2</sup> Cappe, É., Smock, N., & Boujut, É. (2016). Scolarisation des enfants ayant un trouble du spectre de l'autisme et expérience des enseignants: Sentiment d'auto-efficacité, stress perçu et soutien social perçu. L'Évolution Psychiatrique, 81(1), 73-91. doi:10.1016/j.evopsy.2015.05.006





This iterative process led to the development of a unique tool based on an individualised approach.

innovative tool – a questionnaire documenting preferred interests and cognitive strengths, and an intervention guide with school intervention strategies for autistic children aged 6 to 18 attending regular school. This tool allows for an individualised approach, based on the child's interests and strengths. In practice, the questionnaire is filled out by someone close to the child (ideally the children themselves). Then, the questionnaire is handed over to the educator who can independently look up the strategies included in our intervention guide, to find out how to leverage the interests and strengths identified in the questionnaire. An information section, included in the guide, will help educators to better understand learning processes in autism.

To build this questionnaire, we began with a literature review on preferred interests and cognitive strengths in autism. From these sources, we extracted a first list of strengths and interests often found in autism. Some items were inspired by or directly pulled from existing questionnaires. A preliminary version of the questionnaire was then revised by autism experts. Experts were asked to rate how clear, concise, and appropriate to its category (strength or interest) each item was. Items with low scores on all three aspects were removed and other items modified according to expert suggestions. A preliminary version of the intervention guide was then created based on current evidence for autism interventions. Alongside this process, we collected scientific material on how autistic people learn, to include in an information section of the guide. The same revision method used for our questionnaire allowed us to refine the guide. A preliminary version of the guide was therefore presented to autism experts, who rated the clarity and conciseness of each item as well as the appropriateness of the intervention suggested for each interest and strength. Low scoring items were removed or revised. Experts also provided comments on the guide's user instructions and structure, which we integrated. Both sections of this tool thus underwent content validation, in order to ensure that the interventions suggested were relevant to the interests and strengths identified.

This iterative process led to the development of a unique tool based on an individualised approach. It allows for close identification of the child's strengths and interests, which could be of use in educational settings to allow the child to reach their full potential. Unlike other available tools, this questionnaire and guide do not require training in psychometrics. However, we do not intend to replace recommendations issued by resource staff, but rather to offer a tool which complements professional expertise and other measures. The questionnaire can be used alone or with the intervention guide. The intervention guide offers multiple strategies to implement and promote learning.

The questionnaire and guide will be available in the spring 2021 on the RNETSA website, along with an introductory video to guide tool use. We are currently working on an adapted version of this tool for residential settings, to be made available in the spring. The full thesis project will be available shortly at the following address: http://di.uqo.ca/

#### Reference:

St-Laurent, A. (2020). Développement d'un outil de mesure et d'un guide d'intervention à l'utilisation des intérêts de prédilection et des forces cognitives en milieu scolaire chez les enfants et adolescents autistes de 7 à 18 ans [mémoire de maîtrise, Université du Québec en Outaouais, Canada]. http://di.uqo.ca/.