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RÉSEAU NATIONAL D'EXPERTISE EN TROUBLE DU SPECTRE DE L'AUTISME

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



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Sur le spectre: Autism research more accessible.

It is once again with great pride that we present to you a new issue of our scientific outreach magazine, Sur le Spectre, brought to you by the Montreal Cognitive Neuroscience and Autism Research Group.

With this issue of Sur le Spectre, our team has continued to grow, with new authors volunteering to write articles aimed at increasing the accessibility of autism research.

In this issue, you will find the next article in our "Myth busting scientific research" series, which will this time take a closer look at ethics in scientific research. You will also find an article on the neurodiversity movement, which seemed an important concept for us to explain given its potential applications to research. We have also included summaries of two articles recently published by our research group, as well as an outline of the main takeaways from a recent conference looking at diagnostic practices in autism. Lastly, you will find a summary of an article on empathy in autism. We encourage you to consult the original articles referenced by our authors if you would like further information on topics of interest.

Our partners have also grown for this issue, which we are extremely grateful for! We are pleased to now benefit from the support of the Marcel and Rolande Gosselin Research Chair in Cognitive Neuroscience and Autism. We would also like to take this opportunity to officially thank our partners who have renewed their support issue after issue: the Réseau National d'expertise en TSA (RNESAT) and the Fondation des Petits Trésors. Thank you again to all our research participants, who make the advancement of research possible. We hope that you enjoy the two articles summarizing key findings from articles recently published by our research group, for which our participants made several trips to Rivière-des-Prairies Hospital in order to take part in these two studies.

Lastly, we would like to note that with our 7th issue, we are also approaching the 2,000 subscriber milestone for our newsletter. A huge thank you to our readers, please do not hesitate to consult our website (www.autismresearchgroupmontreal.ca) and like our Facebook page to stay updated on the group's activities. Invite your colleagues to sign up for our newsletter in order to receive every issue of Sur le Spectre as soon as it is published.

Happy reading! 



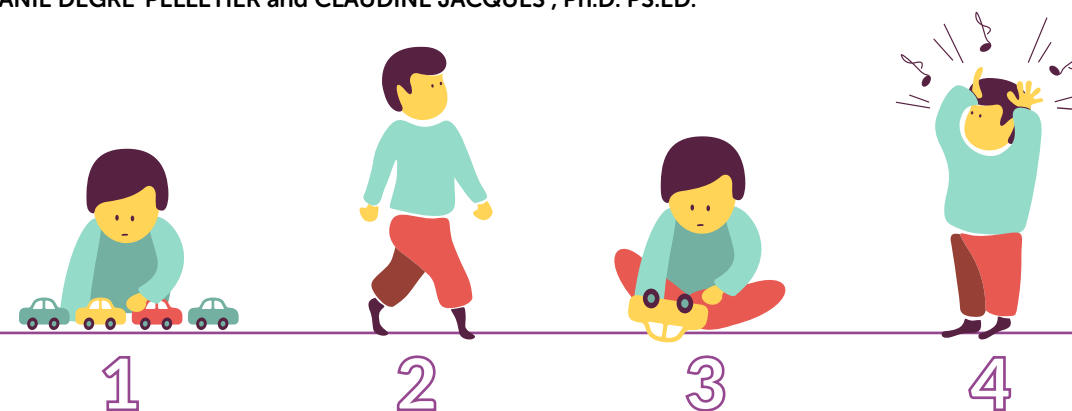
Valérie Courchesne Ph.D.
 Chief editor

With this 7th issue, we are approaching the 2,000 subscriber milestone for our magazine. A huge thank you to our readers.



Are repetitive behaviours and object exploration in young autistic children compatible?

By JANIE DEGRÉ-PELLETIER and CLAUDINE JACQUES, Ph.D. PS.ED.



The DSM-5's second diagnostic domain is made up of four components:

- 1 Repetitive language, use of objects and movements (e.g. hand flapping, finger flicking, echolalia, lining up objects),
- 2 excessive adherence to routines, rituals, and resistance to change (e.g. always preferring the same route),
- 3 restricted or highly-focused interests (e.g. dinosaurs, cars, traffic lights),
- 4 hyper or hypo sensitivity to sensory stimulation, or unusual interest for certain sensations (e.g. lateral gaze, close staring, covering ears, sniffing objects).

Repetitive behaviours, which are included in the second diagnostic domain of autistic signs, are still perceived rather negatively by the medical and clinical establishment when compared to sociocommunicative signs. Indeed, we frequently hear that these behaviours interfere with daily functioning, attention and exploration of one's environment in autistic individuals, thereby lessening learning opportunities. But what if these behaviours served a more adaptive purpose than previously thought? Do these behaviours allow autistic people to explore their environment in their own way? Can we use autistic children's repetitive behaviours to guide learning?

It was these questions which led researcher Claudine Jacques to develop the Montreal Stimulation Situation (Situation de Stimulation de Montréal, or SSM in French) 10 years ago. This innovative play-based situation aimed to study and compare repetitive and stereotyped behaviours and object exploration in autistic and typically developing children. An article recently published in PLoS ONE details research findings based on 49 autistic and 43 neurotypical pre-school children exposed to the SSM.



Do these behaviours allow autistic people to explore their environment in their own way?



In terms of object preference, autistic children demonstrated more interest (in terms of frequency and duration) in literacy-related objects, such as books, dictionaries, and magnetic letters and numbers.

The **Montreal Stimulation Situation** lasts 30 minutes and is conducted in a play room stocked with 40 objects of interest to young autistic children (e.g. toy cars, miniature letters and numbers, trains, tablet etc.). The task is separated into 4 phases:

- 1 (1) Free play phase 1 (5 minutes), where the child is free to explore all objects in the room
- 2 (2) Semi-free play phase (5 minutes) where the child again explores objects in the room, but the experimenter activates or turns on the objects the child plays with
- 3 Semi-structured play phase (15 minutes) where the experimenter presents 11 objects hidden in a box in a successive manner, allowing the child to explore all available objects
- 4 Free play phase 2 (5 minutes), where the child is free to explore all objects in the room.

What has the MSS found?

The results of this initial study using the MSS represent a first step towards redefining repetitive behaviours in autism. Firstly, this study confirmed that autistic children demonstrate more and longer lasting repetitive behaviours than typically developing children. The most frequent repetitive behaviours observed in autistic children during the situation were hand mannerisms (flapping), visual exploration (close up staring) and arm movements. The MSS also enabled an important discovery regarding childrens' exploration of their environment. As it turns out, autistic children explore the same number of objects for a similar duration of time as typically developing children. In terms of object


preference, autistic children demonstrated more interest (in terms of frequency and duration) in literacy-related objects, such as books, dictionaries, and magnetic letters and numbers.

What do these findings suggest?

Contrary to widespread negative perceptions of repetitive behaviours, this study implies that, when allowed to explore a variety of objects in a stimulating and interesting environment, repetitive behaviours do not lead to less exploration of the environment. This begs us to reconsider the very principles of some autism interventions. Many such interventions aim to render the environment as uninteresting as possible by minimizing "non-social" distractors, aiming to reduce repetitive behaviours and therefore maximise learning.

What now?

With a larger number of participants, we would like to better understand how repetitive behaviours change over time, depending on age, gender and cognitive abilities of autistic and typically developing children, as well as children with developmental delays. We predict that certain repetitive behaviours and preferred interests will later determine cognitive development in autistic children.

To study these hypotheses, a larger number of children are needed and recruitment is therefore ongoing. If you would like your child to participate, whether autistic, typically developing (no diagnosis) or presenting with developmental delays, please contact our team by phone (514-619-3505) or email (recherche.autismemtl@gmail.com). 

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Conventional intelligence tests, developed for use in preschool-aged children, are not adapted to the developmental characteristics of autistic children at this age.

Assessing intelligence in autistic preschoolers:

mission impossible?

By AUDREY MURRAY

One of the biggest challenges clinicians face when diagnosing autistic children is accurately assessing intellectual potential, especially in preschool-aged children. In an effort to investigate this issue, the Montreal Autism Research Group recently published findings in the Journal of Autism and Developmental Disorders.

Why not use traditional intelligence tests?

Conventional intelligence tests, developed for use in preschool-aged children, are not adapted to the developmental characteristics of autistic children at this age.

For example, an autistic child may fail a task because they did not understand the verbal instructions, or simply because the material did not interest them. Since evaluating children this early in their development is difficult, they are often left out of studies. Therefore, little is known about the intellectual profile of very young children.

With this study, the researchers sought to document the intellectual profile of preschool-aged autistic children, by comparing results obtained with conventional testing vs. "strength-based" testing.

What do we mean by "strength-based" testing?

Strength-based assessment tools include all tests on which autistic people generally perform well. These tests seem adapted to the way autistic people think and problem-solve, and are often grounded in perception. Language use is overall quite minimal: there are no instructions and no verbal response is required. Rather, these tests rely on making all information needed

to complete the task readily available, without requiring any prior knowledge or learning from the child. One example of a strength-based test is Raven's colored matrices. This test involves completing a succession of logical steps by finding the missing piece amongst a selection of pieces. The child has access to all material and can directly place the piece in the appropriate place.

Conventional test

Mullen Scales of Early Learning (MSEL)



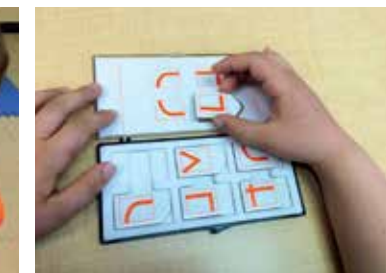
Conventional test

Wechsler Intelligence Scale for Children (WPPSI-IV)



Strength-based test

Raven's Colored Progressive Matrices (RCPM)



The article's authors report that autistic people tend to perform better with these kinds of "visual" tasks than with conventional tasks, and furthermore that they are linked to their intellectual ability. The task is quick and easy to administer, which also makes it ideal when assessing intellectual potential in young children. This article is actually the first to compare scores obtained by preschool-aged children on these two types of tasks.

A "flexible" assessment method

Beyond the use of strength-based testing, the authors also propose a flexible assessment method. Contrary to conventional methods, where tasks must be administered in a specific order and instructions strictly adhered to, flexible methods emphasize individualized assessment.

For example, let us take a child who, instead of imitating the examiner drawing a small circle within a larger circle, spontaneously draws a car. To illustrate the car's wheels, he then draws a small circle within a larger circle. Whilst the child did not exactly follow instructions to copy the examiner, the flexible method still allows for assessment of fine motor skills using the child's spontaneous drawing. Tasks can also be administered in any order deemed fitting, and the child may have access to tools that can help them respond (for example, using a token to indicate the right answer instead of pointing).

The purpose of flexible testing is to make full use of available time by adapting to the characteristics of every child, thereby maximizing opportunities to access their full intellectual potential. With this method, examiners try to evaluate the maximum abilities of young children, instead of their capacity to conform to traditional assessment.

What do we see when using strength-based, flexible testing?

This study's cohort was based out of Rivière-des-Prairies Hospital, and made up of 52 autistic and 54 neurotypical children aged 2 to 6 years. Each child was evaluated using the flexible method, with two conventional tests (Mullen Scales of Early Learning (MSEL) and the Wechsler Intelligence Scale for Children (WPPSI-IV)) and one strength-based test (Raven's Colored Progressive Matrices (RCPM)) administered.

First, researchers measured preschool-aged children's ability to complete intelligence testing. It did not come as a great surprise that younger children were more difficult to assess, and required longer testing. Assessments also tended to last longer with autistic children than neurotypical children. However, the team also found that assessment length was not related to performance! What this tells us is that accurate assessment

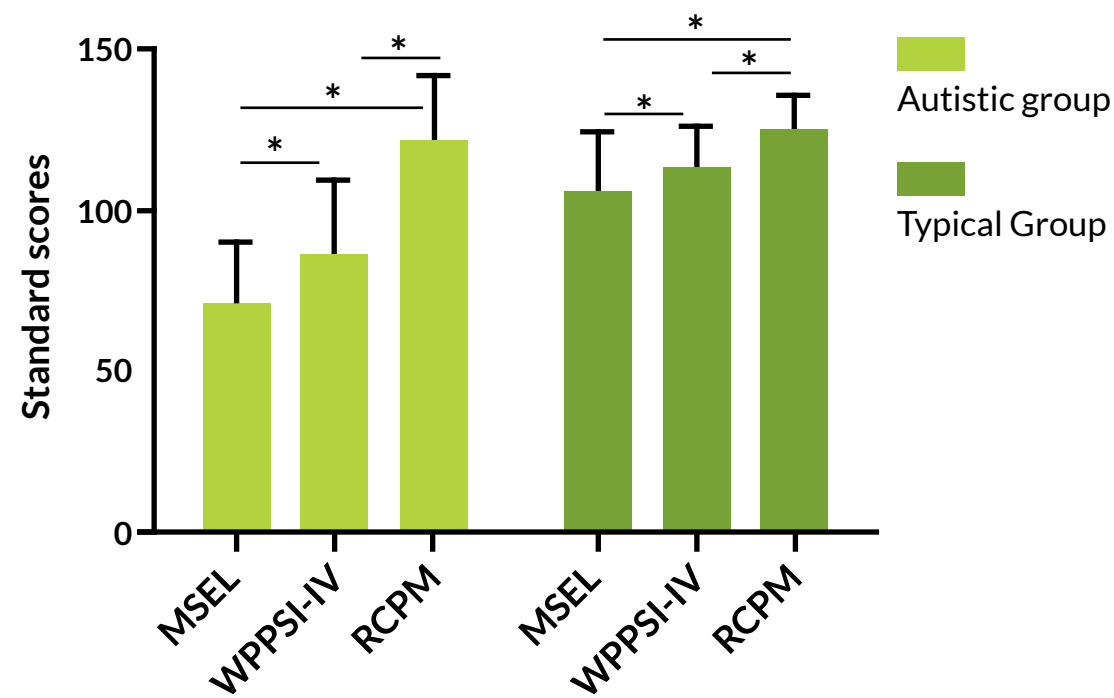
Whilst the child did not exactly follow instructions to copy the examiner, the flexible method still allows for assessment of fine motor skills using the child's spontaneous drawing



It highlights the importance of using a variety of tests to assess the full intellectual potential of autistic children, and to decrease the risk of underestimating their abilities.

of very young autistic children requires perseverance, several appointments, and time. Indeed, these findings demonstrate that difficulties with testing an autistic child do not actually translate to intellectual difficulties in that same child.

Researchers then evaluated the intellectual profile of study participants. Results indicate that, despite disparities in performance on conventional tests between the two groups, autistic children demonstrate satisfactory performance on strength-based assessment.



This highlights the importance of using a variety of tests to assess the full intellectual potential of autistic children, and to decrease the risk of underestimating their abilities. These results are promising, and may inform clinicians and researchers in selecting tools and methods that allow for a full and thorough assessment of intellectual potential in young autistic children.

Original article: Courchesne, V., Girard, D., Jacques, C., & Soulières, I. (2018). Assessing intelligence at autism diagnosis: mission impossible? Testability and cognitive profile of autistic preschoolers. *Journal of autism and developmental disorders*, 1-12.

Autism in child psychiatry:

epidemic or artificial trend?

By PASCALE GRÉGOIRE, MD, FRCP (C) and LAURENT MOTTRON, MD, Ph.D.

Are rising autism rates indicative of a true increase in prevalence, or a consequence of the way our healthcare system is organized? This was the question addressed on January 17th and 18th at the "Autism: 2019 perspectives/ epidemic or artificial trend?" conference held in Montreal. The event was organized by the Autism Program at Rivière-des-Prairies Mental Health Hospital, of the CIUSSS du Nord-de-l'Île-de-Montréal, and with the support of the Petits Trésors Foundation. The organizers were psychiatrists dedicated to improving service delivery in Quebec and disseminating accurate clinical and epidemiological information. The 22 speakers included psychiatrists and representatives from the education and public health sectors of Sherbrooke, Québec City and Montreal, who presented to around 500 participants on various issues and mechanisms driving the epidemic increase of autism diagnoses in Quebec.

The speakers unequivocally concluded, based on a careful analysis of autism assessment referrals suggesting a steady decrease in the number of autism diagnoses received from such referrals, that we are currently witnessing an artificial increase in autism diagnoses. The nature of diagnostic tools, diagnosis-based access to educational services, the existence of specialized autism classrooms, and the quest for a sole, targeted diagnosis rather than the consideration of multiple possible diagnoses, equally contribute to this artificial increase. This reality simultaneously harms autistic people, whose autism-specific services will be made available for other conditions, and those falsely

diagnosed as autistic, who will not receive appropriate services. The rising number of autism cases in Quebec is not attributable to any biological phenomenon, epidemic, or related trend. Differences in prevalence across regions are a reflection of whether a diagnosis is required to obtain services, rather than the result of thorough assessments made by a team of experts.

We must reconsider *targeted* screening for a main diagnosis of autism. In effect, this diagnosis is often dropped following specialized assessment, where clinicians will identify other diagnoses. However, we must preserve expert clinics exposed to a large number of autistic people of all ages. This is necessary in order to maintain clinical expertise, train competent professionals to diagnose this condition (when truly present), and to contribute to scientific research.

Whilst child psychiatry has contributed to the increased recognition of autism diagnoses (and must continue to do so), the link between diagnosis and services must be fundamentally reconsidered, and it is this task which awaits our new government. The apparent increase in autism diagnoses is actually the result of a faulty organization of care, in which a growing number of children will see autism as their only hope to gain access to services. The conference's conclusion was firm: services must be delivered according to need and not the nature of diagnosis. Diagnosis must determine the content of services, but not whether they are obtained in the first place.

The apparent increase in autism diagnoses is actually the result of a faulty organization of care, in which a growing number of children will see autism as their only hope to gain access to services.



Neurotypical: a term used to describe people with typical brain development (non-autistic people)

A new look at empathy in autism

By NOÉMIE CUSSON

We often hear or read that autistic individuals lack or have diminished empathy, a statement confirmed by most studies up until now. However, this conclusion does not mirror the experiences of autistic people, who often report feeling just as much empathy as **neurotypical** individuals. What could explain this gap between scientific literature and personal experience?

Part of the answer could be that studies tend to use scenarios developed for neurotypical people. This is problematic because empathy is facilitated when the observer can relate to the person they are observing. Since most autistic people feel different from their neurotypical peers from a young age, this could contribute to observations of reduced empathy as reported in these studies. Thus, a Japanese research team led by Hidetsugu Komeda decided to investigate whether using scenarios constructed specifically for autistic people would give different results when measuring empathy in autistic individuals.

To test this, 15 autistic adults without intellectual disabilities (14 men and 1 woman) and 15 neurotypical adults (13 men and 2 women) were asked to read sentences describing either an autistic or a non-autistic character while lying in a brain scanner (an fMRI). One of the sentences used was the following: "Yuya (a Japanese male name) would rather be alone than with others".

The participants had to judge how similar they felt to the characters described in the sentences and whether they agreed or not with the sentences. At the same time, the brain scanner measured activity in a part of the brain

called the ventromedial prefrontal cortex (vmPFC), which is involved in empathy and in processing self-related information.

The researchers found that neurotypical participants tended to recognize themselves in sentences describing non-autistic (i.e. neurotypical) characters. On the other hand, autistic individuals recognized themselves just as much in sentences describing autistic and non-autistic characters. The researchers interpreted this finding as a relative lack of self-awareness in autistic individuals, because autistic participants did not report feeling more similar to autistic characters. However, results from the brain scanner painted a slightly more complex picture.

In terms of brain activity, ventromedial prefrontal cortex (vmPFC) activation was significantly greater in autistic individuals when they judged sentences describing an autistic character than when they judged sentences featuring a non-autistic character. An opposite brain activity pattern was observed in neurotypical people; the ventromedial prefrontal cortex activation was greater when neurotypical participants judged sentences describing non-autistic individuals than when they judged sentences describing an autistic person.

These findings are important, because they show that autistic people, just like neurotypical people, feel more empathy towards those who are similar to them. This could explain why previous studies, which used scenarios built for neurotypical individuals, found an empathy deficit in the autistic population. From a clinical point of view, these results suggest that autistic individuals may be well positioned to help others with autism, as they do have empathy 🌱



FAQ: research ethics

By CAMILLE LETENDRE

Intro

For many of us, scientific research seems mysterious and raises plenty of questions. What are the practical purposes of research? How do research projects take place? Which specific issues must researchers consider? Though a far cry from lab rats and the iconic white coat-clad, disheveled scientist, we invite you for a second time to come along as we take a closer look into the world of autism neuroscience research.

Introduction of the article

Research ethics is a large and indispensable part of developing and conducting research projects on human beings. It is a code of conduct of sorts, meant for researchers and based on values of respect, justice, personal well-being, and all other principles underlying human dignity. In order to ensure that ethical considerations are taken into account in research projects involving human beings, all projects without exception are subjected to rigorous assessment by a Research Ethics Committee (REC).

Here are five questions related to research ethics, which are often asked by people who participate in projects conducted by the Montreal Cognitive Neuroscience and Autism Research Group.

It is a code of conduct of sorts, meant for researchers and based on values of respect, justice, personal well-being, and all other principles underlying human dignity

It is crucial that you take the necessary time to read the information and consent form before participating, in order to give informed consent

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Questions and answers

1 How can I make sure that a project I would like to participate in has been approved by an REC?

When an REC approves a research project that will take place in one of its establishments, it stamps the consent form with a seal of approval, which includes the date of final approval.

2 Why is it important to read the information and consent form prior to participating in research?

It is crucial that you take the necessary time to read the information and consent form before participating, in order to give *informed consent*. This form contains all the information you need to understand what your participation implies, such as what will be required of you, benefits of participating, risks and inconveniences, and freedom to withdraw at any point. If anything remains unclear or you have any questions about the form, do not hesitate to address all questions to the researcher or their representative, until you receive satisfactory answers that allow for an informed decision to participate in the study. Signing the consent form confirms that you have read and understood it, that your questions have been answered and that you consent to participate in the study according to the described terms and conditions... which is why it is so important to read them!

3 I would like for my child to participate in a research project. My child is underaged, must they still provide consent?

Underaged participants are considered a vulnerable population, which includes any person with diminished

decision-making abilities, due to their young age or mental state. Therefore, a parent or guardian must consent for the child to participate in the study. However, in cases where a child is able to comprehend the nature of their participation, their verbal or written assent will be taken into account.

4 If I participate in a research project, will my personal information be made publicly available?

La confidentialité et le respect de la vie privée sont des principes cruciaux en éthique de la recherche. Le chercheur ne peut communiquer les données recueillies sur un participant à une autre personne sans son consentement et se doit de protéger ces données. Les mesures prises par le chercheur pour respecter la confidentialité varient selon la nature des projets de recherche et sont énoncées dans le formulaire d'information et de consentement. Concrètement, il pourrait s'agir par exemple de « coder » les renseignements personnels, c'est-à-dire d'attribuer un code au participant pour remplacer son nom, ou de recueillir les données de façon anonyme, de sorte qu'aucun renseignement permettant d'identifier la personne ne soit consigné.

5 Why do some studies financially compensate participants?

Monetary compensations are provided in certain research projects in order to "compensate" for any inconveniences, such as travel and time commitments. For example, this could be a fixed sum of money, reimbursement for parking or travel, or sometimes an hourly sum.



Neurodiversity:

A concept applicable to research

By PETER CROSBIE, JULIE CUMIN and JÉRÔME LICHTLÉ

Neurodiversity, a term first coined by Australian sociologist Judy Singer in 1999, is a new manner of describing all the ways in which human brains differ. We speak of neurodiversity when describing autistic and dyslexic people, or those with ADHD, because their way of thinking and seeing the world differs from that of the majority, which we refer to as "neurotypical". Rather than viewing these differences as disorders, neurodiversity sees these conditions as natural, legitimate, and worthy of respect and inclusion in our society. However, this does not deny that certain specificities linked to autism or other conditions may manifest as a disability in some situations. Simply put, proponents of the neurodiversity movement recognize the challenges that autistic people face, but also their potential.

The neurodiversity movement advocates, amongst other things, for the active participation of autistic people in research that concerns them. This type of engagement can actually benefit research and autistic people around the world. Indeed, autism research was long conducted without the direct implication of autistic people. Many clinicians and researchers thought that autistic people were not capable of contributing to research, whether it affected them or not. Autistic researchers, such as Damian Milton and Michelle Dawson, proved this idea wrong by making important contributions to science. Their work demonstrated not only that autistic people were able to conduct research, but that certain traits linked to their autism in fact made them stand out as top researchers. The neurodiversity movement encourages us to value

Their work demonstrated not only that autistic people were able to conduct research, but that certain traits linked to their autism in fact made them stand out as top researchers.

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Research assumed for many years that autistic people were lacking in empathy. This hypothesis was sharply critiqued by autistic people, who instead argued that the issue was one of how empathy was defined



autistic people's research contributions. Even with these ideas gaining wider traction, scientific research involving autistic co-investigators remains relatively uncommon.


The neurodiversity movement also considers that autistic people should be consulted when determining priorities on research that concerns them, as is best put by the slogan, "Nothing about us without us". One of the aims of research on any minority is to improve quality of life in that population. Autistic people, as with any other minority, have opinions on what is important to them, which does not always coincide with what researchers or funding organizations deem important. A British study actually illustrated this point by demonstrating that areas of research prioritized by autistic adults were amongst the least funded. For example, research on adapting public services to the needs of autistic people, which autistic participants listed as a top priority, received only 5% of research funding between 2007 and 2011. It is therefore crucial that autistic people are given a voice if we are to prioritize research that will improve their quality of life.

Lastly, the neurodiversity movement has over the years highlighted several instances in which autistic people found that research published about them did not mirror their experiences. This has furthered research in numerous cases, by encouraging the revision of previously established theories. For example, research assumed for many years that autistic people were lacking in empathy. This hypothesis was sharply critiqued by autistic people, who instead argued that the issue was one of how empathy was defined. Autistic researcher Damian Milton notably suggested a "double empathy problem", suggesting that difficulties with social interaction between autistic and non-autistic people were not unidirectional, but rather a case of mutual misun-

derstanding. For further information on this topic, we encourage you to consult Noémie Cusson's article in this issue (page 10).



In viewing autism as a different way of functioning, neurodiversity can advance research, by forcing us to reconsider what we consider "normal" behavior. For example, a recent study analyzing interactions between autistic people playing video games identified several autism-specific behaviors used to facilitate social exchanges, despite the fact that these interactions may seem incoherent to non-autistic people. The authors namely cited conversations made up entirely of movie quotes, which seemed to promote social understanding between these young autistic adults.

In conclusion, neurodiversity does not necessarily signify "good science", nor does it represent a seal of approval from the entire autistic community, or justify all actions undertaken in its name. However, by accepting that all human conditions have equal value, and that autistic people have the right and the ability to guide research and policy that affects them, we can simultaneously accept and develop people's strengths, without denying specific needs inherent to each condition. 

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