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# Autism-Related Language Preferences of French-Speaking Autistic Adults: An Online Survey

Philippine Geelhand,<sup>1</sup> Fanny Papastamou,<sup>1,2</sup> Marie Belenger,<sup>1,\*</sup> Elise Clin,<sup>1,\*</sup> Lydia Hickman,<sup>3</sup> Connor T. Keating,<sup>3,†</sup> and Sophie Sowden<sup>3,†</sup>

# **Abstract**

**Background:** In recent years, there have been increasing discussions surrounding the appropriate terminology to talk about autism. Initially, this debate revolved around the use of person-first language (e.g., person with autism) versus identity-first language (IFL; e.g., autistic person) but has recently expanded to other autism-related terms (e.g., deficits). However, to date, studies investigating autism-related language preferences have been limited to English-speaking countries, and little is known about preferences in other languages. This study addresses this gap by investigating the language preferences of French-speaking autistic adults.

**Methods:** Five hundred and forty-one French-speaking autistic adults (formal diagnosis and self-identified) completed an online survey where they selected terms they preferred to use to talk about: (1) the nomenclature of autism; (2) an autistic person; (3) someone's autistic identity; (4) autism more broadly; (5) the abilities of autistic people; and (6) people without a diagnosis of autism. Participants also revealed more about their language preferences via an open-text response.

**Results:** The most preferred terms were "Autisme," "Personne autiste," "Autiste," "Est Autiste," "Différence neurologique/cérébrale," "Différences," "Difficultés," "Personne neurotypique," "Neurotypique," and "Personne non-autiste." To better understand these preferences, participants' open comments were analyzed, revealing further support for IFL and the social model of disability, and a preference for simple, precise, and validated terms.

**Conclusions:** These results are consistent with autism terminology preferences in English-speaking countries and provide additional insight into the reasons underlying these preferences. Such work has implications for informing the language of researchers, clinicians, and other professionals in the field, as well as the general public.

**Keywords:** language preferences, autism, French, neurodiversity

# **Community Brief**

Why is this an important issue?

More and more research is investigating which words should be used to talk about autism. Initially, this discussion revolved around the use of person-first language (e.g., person with autism) versus identity-first language (e.g., autistic person) but has recently expanded to other autism-related terms (e.g., disorder, deficits,

<sup>&</sup>lt;sup>1</sup>ACTE at LaDisco and ULB Neuroscience Institute, Université libre de Bruxelles, Brussels, Belgium.

<sup>&</sup>lt;sup>2</sup>Center for Research in Cognition & Neurosciences (CRCN), Université libre de Bruxelles, Brussels, Belgium.

<sup>&</sup>lt;sup>3</sup>Centre for Developmental Science, School of Psychology, University of Birmingham, Birmingham, United Kingdom.

<sup>\*</sup>Both these authors are co-third authors.

<sup>&</sup>lt;sup>†</sup>Both these authors are co-last authors.

high-functioning autism). To date, all the studies on this topic have focused on language preferences in English-speaking countries, and little is known about preferences in other languages.

# What was the purpose of this study?

We wanted to know whether French-speaking autistic adults would show similar or different autism-related language preferences than English-speaking autistic individuals. We also wanted to know the reasons for these language preferences.

# What did the researchers do?

In an online survey, we asked 541 French-speaking autistic adults around the world what terms they prefer to use to talk about (1) the nomenclature of autism, (2) an autistic person, (3) someone's autistic identity, (4) autism more broadly, (5) the abilities of autistic people, and (6) someone without an autism diagnosis. Participants also had the opportunity to tell us more about their language preferences in an open comment.

# What were the results of this study?

The most preferred terms were "Autisme," "Personne autiste," "Autiste," "Est Autiste," "Différence/neurologique," "Différences," "Difficultés," "Personne neurotypique," "Neurotypique," and "Personne non autiste." To better understand the reasons underlying these preferences, participants' open comments were analyzed, revealing further support for identity-first language and the social model of disability, and a preference for simple, precise, and validated terms.

# What do these findings add to what was already known?

We previously knew about language preferences of English-speaking autistic people. This study extends these findings by showing that French-speaking autistic adults also prefer terms that reflect the ideas of identity-first language (e.g., "Est Autiste," "Personne autiste") and the social model of disability (e.g., "Différence," "Handicap"). We also show that these are not the only reasons behind language preferences: Term simplicity, precision, and validity are also important when talking about autism.

# What are the potential weaknesses in the study?

The reported preferences are not representative of all autistic individuals, as our sample did not include children and adolescents. In addition, we did not make specific adaptations to our questionnaire for non-speaking people or people with intellectual difficulties, so we do not know to what extent their opinions are represented in our data. Further, recruitment was done almost exclusively online, resulting in a self-selecting recruitment method for our sample (i.e., participants who have access to Internet and a computer). Finally, participants who responded to the advertisements and completed the questionnaire are probably interested in the debate regarding language to talk about autism. Therefore, our sample may be more representative of the online autistic, pro-neurodiversity community.

# How will these findings help autistic adults now or in the future?

This study is the first to look at the language preferences of French-speaking autistic adults. Further, our results have substantial implications for informing the language of researchers, clinicians, and other professionals in the field, as well as the general public.

# Introduction

In RECENT YEARS, there has been a growing interest in the language used to talk about autism and people who are autistic. 1-7 This interest is not trivial as the words we use can shape our representations of the world. 8 Further, the language used to describe autistic individuals is not just descriptive, and it can have real-life consequences. Autistic people experience stigma, 9 which is triggered by and reflected in the use of demeaning terms. 6.7 As such, one important step in reducing stigma is to change the way we talk about autism to reflect the opinions of the people directly affected by this issue.

To date, the debate about autism-related language use has primarily revolved around the use of person-first language (PFL) versus identity-first language (IFL). In PFL, the noun referring to a person precedes the phrase referring to a disability (e.g., person/individual *with autism*). In contrast, in IFL, the disability (in the form of an adjective) precedes the noun referring to the person (e.g., *autistic* person). In addition to differences in linguistic structure, PFL and IFL reflect different ideas about disability. <sup>7,10</sup>

Some advocates argue that by literally putting the person first, PFL emphasizes the person rather than their disability, indicating that the disability is not the only defining feature of the person's identity but one among many other features.<sup>7,10,11</sup>

Although the use of PFL was encouraged to reduce stigma toward disabled people, many scholars and self-advocates have argued that PFL actually perpetuates stigma. <sup>2,6</sup> For example, Gernsbacher <sup>12</sup> found that PFL is used more often to refer to children with disabilities (e.g., children with autism) than to refer to children without disabilities (e.g., children with typical development). Conversely, IFL is used more frequently to refer to children without disabilities (e.g., typically developing children). Further, critics of PFL posit that dissociating the person from their disability (with the preposition "with") suggests that there is something wrong with the disability. <sup>6,7</sup>

According to Botha et al (p. 3), "conceptual (and linguistic) separation of the individual and 'their autism' hurts all those on the spectrum, [...] we formulate an existence or possibility of that life without autism (McGuire, 2016), yet autism cannot, ontically speaking, ever be separate from a person: to combat autism, is to combat autistic people." Many autistic scholars and self-advocates prefer IFL, as they believe it demonstrates that autism is inherent to their identity and cannot be separated from them. <sup>13–16</sup>

Several studies have explicitly investigated the preferences of the autism community regarding PFL and IFL. Kenny et al<sup>3</sup> conducted an online survey to investigate the language preferences of different members of the autism community in the United Kingdom. Participants were asked to select and rate terms they would use to communicate about autism as well as those they would use to describe themselves or another person with a diagnosis of autism. Respondents fell into four categories: autistic adults, parents, family/friends, and professionals.

Results suggested some disagreement regarding preferences for PFL or IFL among the stakeholders. For example, autistic adults, family members/friends, and parents endorsed the term "autistic" to a larger extent than professionals. Conversely, although the term "person with autism" was endorsed by almost half of the professionals, a few autistic adults and parents endorsed it. Bury et al<sup>4</sup> extend this line of research to Australian autistic adults.

The authors found that the IFL term "autistic" was polarizing, with most participants ranking it as either least offensive or most offensive (while a few participants ranked it in the middle). The terms "autistic" and "person with autism" yielded some disagreement across stakeholders, whereas other terms such as "autism" and "on the autism spectrum" yielded more consensus as they were equally appreciated by autistic people, their families, and professionals.<sup>3,4</sup>

By focusing primarily on PFL and IFL, the adequacy of other terminology choices to talk about autism—such as the description of the abilities of autistic people (e.g., deficits, difficulties, differences) or autism more broadly (condition, disorder, disability)—has received little attention to date. However, just like PFL and IFL, these terms are not neutral and also influence our understanding of autism. Two models have been put forward to describe these different conceptualizations of autism: the social and medical models of disability (see Bottema-Beutel et al, <sup>2</sup> for a visual representation of these models).

The social model proposes that disability can result from societal barriers<sup>17</sup> and therefore places emphasis on removing these barriers to overcome the difficulties faced by dis-

abled people, rather than solely focusing on treating their individual impairments.<sup>18</sup> It is important to note that this model does not ignore impairments, and it rather acknowledges that individual challenges (such as physical and mental impairments) and disability (due to an unaccommodating society) can interact.<sup>18,19</sup> Terminological choices, such as preferring IFL rather than PFL, as well as other autism-related terms such as disability instead of disorder can reflect these ideas of the social model.<sup>2</sup>

The social model emerged as a reaction to the medical model of disability.<sup>19</sup> According to this medical view, disability is conceptualized as an individual impairment that limits the person's autonomy and needs to be rehabilitated or cured.<sup>18,20,21</sup> The medical view still prevails in the literature today, which mostly uses a deficit-based discourse about autism.<sup>22</sup> Yet, according to Woods (p. 1092),<sup>23</sup> "the primary social barrier to be removed is the negative language and discourse of the autism label, such as deficit and disorder, along with removing subcategories and sublevels."

For instance, functioning-level descriptors are criticized as perpetuating stigma, while being inaccurate and unable to reflect people's actual skills. <sup>2,24–26</sup> This idea is also mirrored in the findings by Kenny et al<sup>3</sup> that a few respondents (across all stakeholder groups) endorsed "high-functioning autism." Therefore, the discussion about terminology adequacy to talk about autism should revolve not only around the use of PFL or IFL but also around the use of functioning and disorder labels and deficit-based language.<sup>2,5</sup>

Although research has started examining terminology across the world, 3,4,27 findings are still limited to English-speaking countries. This is considering that cross-linguistic differences and similarities are essential to gain a broader perspective on autism-related terminology preferences and to better understand the connotations of different linguistic form. As exposed earlier, in English, IFL and PFL translate into the literal order of words: The adjective expressing identity comes first (*autistic* person) or the noun referring to personhood comes first (*person* with autism).

However, this is not the case for other languages, such as French (personne *autiste* vs. personne *avec autisme*), where the noun referring to personhood always comes first (personne, "person"), with the words referring to the diagnosis coming second, whether it is a prepositional phrase (*avec autisme*, "with autism") or an adjective (*autiste*, "autistic"). Despite these differences in linguistic construction, meanings associated with the English structures can be extended to French.

Just like the PFL expression "person with autism," "personne avec autisme" dissociates autism from the person via the preposition "avec" whereas "personne autiste" does not, as "autiste" is an attributive adjective. In this sense, although "personne autiste" is not structurally IFL, it conveys the same meaning, that is, that autism is inherent to the identity of the person. Although not yet scientifically studied, this question about terminology adequacy generates a lot of interest and discussion on social networks and forums/blogs of French-speaking autistics. <sup>28–30</sup>

In this study, we asked French-speaking autistic adults what terms they prefer to use to refer to: (1) the nomenclature of autism (i.e., the diagnostic labels used to refer to autism as a neurodevelopmental disorder); (2) an autistic person; (3) someone's autistic identity; (4) autism more broadly; (5) the

abilities of autistic people; and (6) people without a diagnosis of autism. We are conscious that the target population (i.e., autistic adults<sup>a</sup>) is not representative of the ideas and preferences of all autistic people. Nevertheless, we think that accounting for their voices is a first step to render autism research and terminology more inclusive.

According to the English-speaking literature on terms to talk about autism, autistic adults prefer terminology that expresses autism as part of the person's identity (IFL). 6,27 As such, we might expect a similar preference in our French-speaking sample. Further, we expect participants to prefer autism-related terms in line with the social model of disability (e.g., differences, condition, etc.) rather than terms reflecting the medical model of disability (e.g., disorder, deficiencies, etc.).

# Methodology

# **Participants**

Five hundred forty-one French-speaking participants completed the questionnaire online ( $M_{\rm age} = 31.09$ , standard deviation [SD] = 10.36, range = 18–70). Of these respondents, 76.3% reported having a formal diagnosis of autism and 23.7% self-identified as autistic. On average, participants who responded as having a formal diagnosis received their diagnosis in adulthood ( $M_{\rm age}$  of diagnosis = 28.91, SD = 11.43, range = 2–68). See Table 1 for demographics.

Most of our participants lived in France (79.6%) and Belgium (12.6%). For more details on the country of birth and residence of our participants, see Supplementary Data SA.

# Translation procedure

We translated the questionnaire designed by Keating et al<sup>27</sup> into French using a forward-backward translation procedure. F.P. and E.C. independently translated the original questionnaire from English to French. These two translations were compared and merged to create a unique French version of the questionnaire. P.G. then translated this French version back to English. Finally, F.P., E.C., M.B., and P.G. met together to compare the two English versions (the original version vs. the version translated from French).

When the two English versions of a question were (quasi)identical, the French translation of that item was maintained. Every difference between the English versions was discussed to reach agreement on the final French translation. Like Keating et al,<sup>27</sup> we used inclusive writing throughout the questionnaire (e.g., "is neurodivergent" was translated as "est neurodivergent·e," which reflects both the feminine and masculine genders). See Table 2 for all original English terms and their translated French equivalents used in the current study.

# Testing procedure

Participants were recruited online almost exclusively via social media (Twitter and Facebook), and a few participants were recruited via autism associations and by mail. Participants accessed the questionnaire on LimeSurvey via a QR

TABLE 1. DEMOGRAPHIC DATA

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	N	%		
Sex assigned at birth				
Female	401	74.1		
Male	121	22.4		
Other	2	0.4		
Prefers not to say	17	3.1		
Gender				
Female cisgender	209	38.6		
Male cisgender	74	13.7		
Non-binary	164	30.3		
Female transgender	16	3.0		
Male transgender	48	8.9		
Prefer not to say	30	5.5		
Diagnosis				
Formal diagnosis	413	76.3		
Self-identified	128	23.7		
Type of diagnosis				
Autism Spectrum Disorder	201	48.7		
Asperger's Syndrome	164	39.7		
Autism/Autistic Disorder	33	8		
PDD-NOS	4	1		
Does not know	6	1.4		
Other	5	1.2		
Other neurodevelopmental/psychia	tric disorders			
Yes	321	59.3		
No	220	40.7		
Medication				
Yes	306	56.6		
No	235	43.4		
Native language				
French	521	96.3		
English	6	1.1		
Spanish	4	0.7		
Ārab	2	0.4		
Portuguese	2	0.4		
Italian	1	0.2		
Romanian	1	0.2		
Czech	1	0.2		
Hungarian	1	0.2		
Turkish	1	0.2		
Cantonese	1	0.2		

PDD-NOS, pervasive developmental disorder-not otherwise specified.

code or a link. Participants who did not meet the following criteria were excluded from the study: (1) being 18 or older (N=18); (2) speaking French fluently (N=5); and (3) having a diagnosis of autism or identifying as autistic (N=3). Participants who completed the questionnaire were entered into a prize draw for 11 gift vouchers of a value of 58 euros each. This study was approved by the Science, Technology, Engineering and Mathematics (STEM) ethics committee at the University of Birmingham (ERN 16-0281AP10).

# Measures

The questionnaire was divided into four parts: (1) information sheet; (2) informed consent; (3) demographic questions; and (4) language preferences questions. In this last section, participants were asked to select which terms they preferred to use to talk about: (1) the nomenclature of autism; (2) an autistic

<sup>&</sup>lt;sup>a</sup>In this study, we restricted our target population to autistic adults as we wanted to replicate as closely as possible the design and methodology of the study by Keating et al. (preprint). Therefore, we did not make any change to the structure of questionnaire, target population nor did we change the recruitment method.

Table 2. Terms Included in the Questionnaire Across Each of the Six Terminology Categories in French (Left Column) with Their English Translation (Right Column)

	French	English
Terms referring to the nomenclature of autism	Syndrome d'Asperger Autisme Condition du Spectre de l'Autisme (CSA Trouble du Spectre de l'Autisme (TSA)	Asperger's Syndrome Autism Autism Spectrum Condition (ASC) Autism Spectrum Disorder (ASD)
Terms referring to an autistic person	Aspie Autiste Personne autiste Personne neurodivergente Personne appartenant au spectre de l'autisme Personne avec autisme/avec un trouble du spectre de l'autisme/avec une condition du spectre de l'autisme	Aspie Autistic Autistic person Neurodivergent person Person on the autism spectrum Person with autism/autism spectrum disorder/autism spectrum condition
Terms referring to someone's autistic identity	A un diagnostic d'autisme/de trouble du spectre de l'autisme/de condition du spectre de l'autisme/de syndrome d'Asperger A de l'autisme/un syndrome d'Asperger Est autiste/Asperger Est neurodivergent · e	Has a diagnosis of autism/autism spectrum disorder/autism spectrum condition/Asperger's Has autism/Has Asperger's Is autistic/Is Aspergic Is neurodivergent
Terms referring to autism more broadly	Condition Handicap Maladie Trouble Différence neurologique/cérébrale	Condition Disability Disease Disorder Neurological/brain difference
Terms referring to abilities of autistic people	Défis Déficits Différences Difficultés Déficiences Performance plus basse/plus élevée Performance plus faible/meilleure	Challenges Deficits Differences Difficulties Impairments Lower/higher performance Poorer/better performance
Terms referring to people without a diagnosis of autism	Personnes allistiques Participant·e·s contrôles Contrôles Contrôles sains Personnes neurotypiques Neurotypiques Personnes non-autistes Non-autistes Personnes typiques Personnes au développement typique	Allistic people Control participants Controls Healthy Controls Neurotypical people Neurotypicals Non-autistic people Non-autistics Typical people Typically developing people

person; (3) someone's autistic identity; (4) autism more broadly; (5) the abilities of autistic people; and (6) people without a diagnosis of autism. See Table 2.

For each of these six terminology categories, participants were first asked to select as many terms as they would be happy to use and then select their favorite (see Supplementary Data SB for results on the favorite terms). After completing these terminology questions, participants had the opportunity to tell us more about their language preferences via an open-ended question. For the full list of questionnaire items, see Supplementary Data SC.

# Data analysis

Participants' responses for the six terminological categories were analyzed in R.<sup>32</sup> Binomial logistic regressions were performed using the glm function. We ran six binomial logistic regressions, one for each terminology category. Each model

included participants' response as the dependent variable (i.e., whether or not participants had endorsed a term) and terminology category (e.g., nomenclature of autism) as the independent variable. *Post hoc* analyses were performed with the emmeans function from the "emmeans" package. Bonferroni correction was used for multiple-comparison correction.

We first conducted these analyses on the whole sample and then conducted them without participants who self-identified as autistic. Results remained the same, except for three contrasts (which did not change the overall pattern of results; see Supplementary Data SD for results of participants with a formal diagnosis only). As self-identifying as autistic did not influence language preferences, we report the results from the whole sample. See Supplementary Data SE for detailed *post hoc* analyses and Supplementary Data SF for a detailed summary of response counts per endorsed term when participants could choose as many terms as they wanted.

To gain further insight into the autism-related preferences of French-speaking autistic adults, we also analyzed participants' responses to the open-ended question (N=297) via a Reflexive Thematic Analysis. <sup>33,34</sup> This technique is particularly suitable for this study as it is amenable to large datasets, <sup>33</sup> sensitive to nuanced meanings within data, <sup>33,35</sup> and facilitates exploration of diverse perspectives. <sup>36</sup> Our analysis is informed from a critical realist ontological position and a contextualist epistemological position, meaning that participants are thought to have an "authentic reality" that is shaped by social and cultural context.

### Results

To ensure that the voices of the participants were not obscured by a heavy theoretical analytical strategy, we adopted an inductive approach to coding. In the first step, both P.G. and M.B. read all responses to familiarize themselves with the data and centralize the voices of the participants within the analytic process. In the second step, P.G. and M.B. independently coded 20% of the comments (N=58) to develop a set of coding categories reflecting the main patterns in the data. In the third step, the authors met to discuss their initial coding categories, resolve any discrepancies, and generate the final set of thematic categories.

In a fourth and final step, P.G. and M.B. used this final set of coding categories to each code half of the remaining comments. Once the coding was complete, the authors discussed the thematic structure again, ensuring that all nuances of the data were represented, and that deviant cases were identified and integrated. Finally, the themes were reviewed for internal consistency and external distinctiveness.

### Quantitative results

To refer to the nomenclature of autism, "Autisme" (90.57%) was the most preferred term, followed by "Trouble du Spectre de l'Autisme" (74.12%), followed by "Syndrome d'Asperger" (34.75%), and finally "Condition du Spectre de l'Autisme" (18.30%) (Fig. 1, Barplot A).

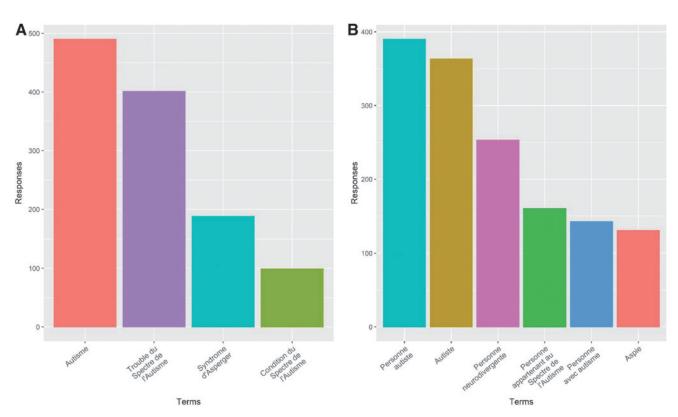
To refer to an autistic person, the most popular terms for referring to an autistic person were "Personne autiste" (72.09%) and "Autiste" (67.10%), followed by "Personne neurodivergente" (46.77%), and finally "Personne appartenant au spectre de l'autisme" (29.57%), "Personne avec autisme" (26.43%), and "Aspie" (24.21%) (Fig. 1, Barplot B).

To refer to someone's autistic identity, the most preferred term was "Est autiste/Asperger" (81.15%), followed by "A un diagnostic d'autisme" (61.37%), followed by "Est neurodivergent e" (45.29%), and then finally "A de l'autisme" (6.28%) was the least popular (Fig. 2, Barplot A).

To refer to autism more broadly, "Différence neurologique/cérébrale" (85.21%) was the most preferred term, followed by "Handicap" (65.99%), followed by "Trouble" (48.06%), followed by "Condition" (40.67%), and then finally "Maladie" (3.33%) (Fig. 2, Barplot B).

To refer to the abilities of autistic people, the most preferred terms were "Difficultés" (84.84%) and "Différences" (79.48%), followed by "Défis" (34.75%), and then finally "Performance plus basse/plus élevée" (16.27%), "Déficits" (13.12%), "Peformance plus faible/meilleure" (11.65%), and "Déficiences" (8.32%) (Fig. 3, Barplot A).

To refer to people without an autism diagnosis, "Neurotypiques" (68.58%), "Personnes neurotypiques" (67.84%),



**FIG. 1.** Participants' endorsement of terms to refer to the nomenclature of autism [Barplot (A)] and of terms to refer to an autistic person [Barplot (B)].

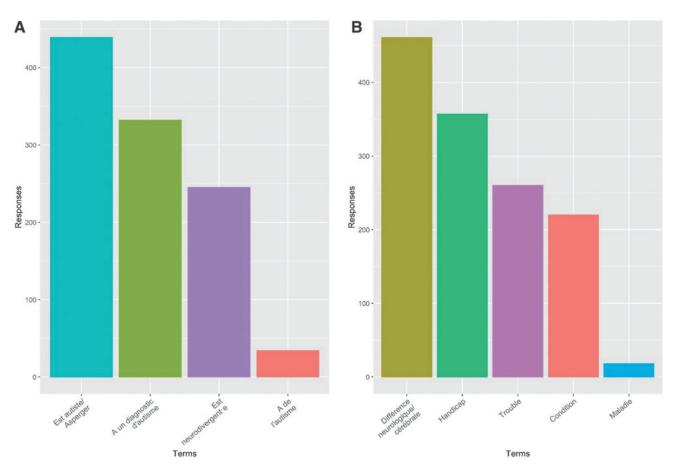
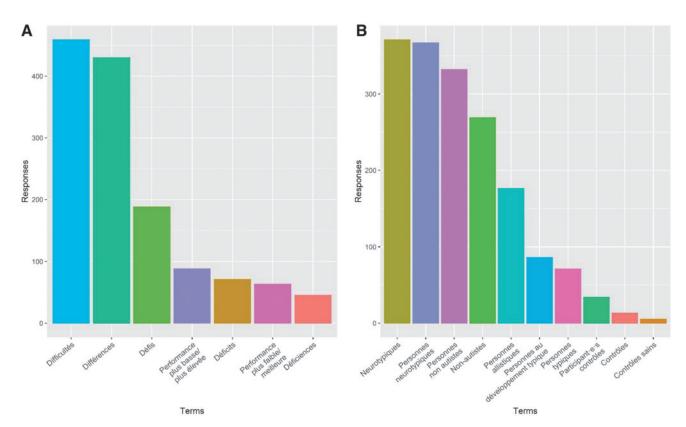


FIG. 2. Participants' endorsement of terms to refer to someone's autistic identity [Barplot (A)] and of terms to refer to autism more broadly [Barplot (B)].



**FIG. 3.** Participants' endorsement of terms to refer to the abilities of autistic people [Barplot (A)] and terms to refer to people without an autism diagnosis [Barplot (B)].

and "Personnes non-autistes" (61.37%) were the most preferred terms, followed by "Non-autistes" (49.72%), followed by "Personnes allistiques" (32.53%), and then finally the least popular terms were "Personnes au développement typique" (15.90%), "Personnes typiques" (13.12%), "Participant · e · s contrôles" (6.28%), "Contrôles" (2.40%), and "Contrôles sains" (0.92%) (Fig. 3, Barplot B).

# Comments analysis

The analysis of the open-ended comments enabled us to identify six main themes in participants' explanations of their language preferences: (1) Autism is inherent; (2) Importance of context; (3) Negative history and connotations; (4) Problems of hierarchy; (5) Don't downplay our difficulties; (6) Use simple terms; (7) Use precise terms; and (8) Use validated terms. See Appendix Table A1 for a description of these themes.

# Autism in inherent

This theme encompasses participants' views on terms that describe autism as inherent to who they are such as "Est autiste," "Autiste" rather than something detachable, or something they can "get" like an illness (e.g., having intestinal problems, having a fever), which is conveyed by terms such as "Personne avec autisme" and "A de l'autisme." They see autism as an inherent attribute, just like being redheaded or small. However, although these individuals see autism as an intrinsic part of who they are, they also highlight that they are not only autistic, just like someone is not only redheaded or small.

J'ai beaucoup de mal avec les termes "atteint d'autisme", "avec autisme" ... J'ai l'impression qu'il y a moi et l'autisme, comme si je cohabitais avec un colocataire. A croire que ça s'attrape. Alors que non, je suis autiste. Cela fait partie de mon fonctionnement neurologique et participe à mon identité propre. C'est ainsi.

I have a big problem with the terms "affected by autism," "with autism." ... I feel like there's me and autism, like I'm living with a roommate. You'd think you could catch it. But no, I am autistic. It is part of my neurological functioning and part of my identity. That's just the way it is.

- [...] Aussi, toute référence a [sic] une personne autiste comme "ayant de l'autisme" ou "personne avec autisme" me mettent mal à l'aise; l'autisme fait partie de nous et est indissociable de nous a [sic] mon sens. Même si on n'est pas QUE autiste. [...]
- [...] Also, any reference to an autistic person as "having autism" or "person with autism" makes me uncomfortable; autism is part of us and inseparable from us in my opinion. Even if we are not ONLY autistic. [...]

# Importance of context

This theme provides important nuances for the interpretation of autism-related preferences. Specifically, some participants reported that they like "Autiste" but only when it is used by other autistic people, and not when it is used by non-autistic people as they often use "autiste" as an insult, to degrade a person (even if they are not autistic).

Je n'aime pas les neurotypiques qui désignent les personnes autistes par « les autistes » car on a l'impression qu'ils nous des-humanise [sic]. Mais en revanche je n'ai aucun mal à me designer [sic] moi-même comme « autiste » et quand d'autres personnes autistes disent « les autistes » cela ne me dérange pas.

I don't like neurotypicals who refer to autistic people as "autistics" because it feels like they are dehumanizing us. But on the other hand, I have no problem referring to myself as "autistic" and when other autistic people say "autistics" it doesn't bother me.

The theme of context was also invoked by participants explaining that autism is not necessarily disabling but can become so in the context of society. More specifically, although autism comes with characteristics that can impair an individual's functioning, most of the problems faced by autistic people are due to the lack of accommodation of our society.

Parler de handicap à propos de l'autisme est intéressant sous le prisme social du handicap; je ne pense pas que l'autisme soit condamné à être un handicap, seulement que dans la société actuelle, avec le peu d'aménagements faits aux habitudes en société, les neurodivergences de l'autisme les handicapent vis à vis [sic] des autres. Par exemple, s'il n'y avait pas constamment de la musique et des lumières vives dans les supermarchés, un certain nombre de personnes autistes n'auraient pas plus de mal à faire leurs courses que les personnes allistes, ou en tout cas beaucoup moins significativement.

Talking about disability in relation to autism is interesting under the social prism of disability; I don't think that autism is condemned to be a disability, only that in today's society, with the few accommodations made to social habits, the neurodivergences of autism are disabling in comparison to other people. For example, if there were not constant music and bright lights in supermarkets, a certain number of autistic people would have no more difficulty in shopping than non-autistic people, or at least significantly less.

# Negative connotations

This theme reflects participants' viewpoints on terms that are associated with negative meanings such as pathologizing terms, the historical background of Hans Asperger (Nazism), and stereotypes (e.g., Rain Man, genius, etc.) that convey a distorted image of autism as well as the person's real needs and abilities.

Le terme "trouble" est stigmatisant car il fait croire que l'autisme est une erreur, doit être soigné, voire guéri, voire doit disparaître. Trouble, maladie, sont des termes faux pour décrire un fonctionnement cérébral différent.

The term "disorder" is stigmatizing because it makes people believe that autism is a mistake, must be treated, or even cured, or must disappear. Disorder, disease, are incorrect terms to describe a different brain functioning.

- [...] Je n'aime pas non plus les termes associés à Asperger, ou pire: les surnoms « mignons » associés à ce nom, comme « Aspie ». L'histoire de Hans Asperger me met mal à l'aise. Comment être fier, ou du moins être en paix avec un syndrome qui porte le nom d'une personne ayant collaboré avec les nazis?
- [...] I also don't like the terms associated with Asperger's, or worse: the "cute" nicknames associated with the name,

such as "Aspie". Hans Asperger's story makes me uncomfortable. How can I be proud of, or at least at peace with, a syndrome that is named after a person who collaborated with the Nazis?

Je n'aime pas lorsqu'on utilise le terme aspie ou asperger pour me désigner car j'ai reçu un diagnostic de TSA (trouble du spectre de l'autisme) et pas asperger. De plus, beaucoup de personnes associent les personnes autistes asperger à des personnes surdouées qui ont peu de difficultés ce qui ne correspond pas à ma réalité.

I don't like when people use the term aspie or asperger to refer to me because I have been diagnosed with ASD (Autism Spectrum Disorder) and not asperger. Also, many people associate autistic aspergers with gifted people who have few difficulties which does not match my reality.

Despite most individuals arguing strongly against the use of these Asperger's-related terms, a few participants expressed some ambivalence toward them. More specifically, although they did not like the negative connotations associated with Asperger's, they still reported using it because it is often better understood by people who are not familiar with or have limited knowledge about autism (e.g., they only know "severe autism").

[...] Par convention sociale et par commodité, j'utilise souvent le terme d'''autisme Asperger'', car je vais "trop bien" pour la plupart des gens, qui ne comprennent donc pas que je puisse avoir un diagnostic d'autisme. Je colle plus à l'image stéréotypée du je-sais-tout Asperger que l'autiste dit "lourd", donc les gens comprennent plus rapidement ma condition quand j'emploie ce terme. Toutefois, je n'aime pas beaucoup cette référence à Asperger, d'une part car il a collaboré avec les nazis pour trier les "autistes éducables" des "autistes non-éducables" [sic] (ces dernier e s étaient envoyé e s dans les camps de concentration), et d'autre part car cette catégorie ne fait désormais plus partie des termes retenus par le DSM-5, si mes souvenirs sont bons.[...]

[...] By social convention and convenience, I often use the term "Asperger's" because I am "too well" for most people, so they don't understand that I might have an autism diagnosis. I fit the stereotypical image of the know-it-all Asperger's more than the so-called "severe" autistic, so people are quicker to understand my condition when I use that term. However, I don't like this reference to Asperger's very much, on the one hand because he collaborated with the Nazis to sort out the "educatable autistics" from the "non-educatable autistics" (the latter were sent to concentration camps), and on the other hand because this category is no longer part of the terms retained by the DSM-5, if I remember correctly.[...]

# Problems of hierarchy

This theme reflects participants' stances on terms that divide the autism community by implying that some individuals are "more" or "less" autistic than others, such as "Syndrome d'Asperger" and its derivative terms ("Aspie," "Est Asperger"), but also on functioning labels that imply a deviance from a (non-autistic) norm (e.g., "déficience," "déficit") or a distinction between "better" and "worse" functioning (e.g., "performance plus faible/meilleure").

J'apprécie peu le terme "asperger", parce qu'il me semble séparer sans cause valable ni raison médicale les personnes autistes "asperger" perçues comme "acceptables" de celles qui le sont moins, ou à l'inverse, d'invalider les besoins, les expériences ou les points de vue des personnes dites asperger. Il est agaçant de voir des personnes non-autistes [sic] faire le distinguo entre "asperger" et "vrais autistes" pour pouvoir continuer à parler en lieu et place des "vrais autistes" dont ils ont décidé qu'ils étaient les porte-parole.

I dislike the term "asperger's" because it seems to me to separate without valid cause or medical reason those "asperger's" autistic people perceived as "acceptable" from those who are less so, or conversely, to invalidate the needs, experiences, or views of the so-called asperger's. It is annoying to see non-autistic people distinguish between "asperger's" and "real autistics" so that they can continue to speak in place of the "real autistics" for whom they have decided they are the spokesperson.

Je déteste que l'on évoque l'autisme comme un déficit, l'étiquette est tellement stigmatisante. Bien sûr, il existe une différence mais en quoi doit-elle être jugée inférieure par rapport à une norme alors que nous avons dautres[sic] compétences? En quoi le monde doit se réduire aux personnes neurotypiques? [...]

I hate it when people talk about autism as a deficit, the label is so stigmatizing. Of course, there is a difference, but how is it to be judged inferior to a norm when we have other skills? Why should the world be reduced to neurotypical people? [...]

# Don't downplay our difficulties

This theme reflects participants' viewpoint on the risk that some terms may minimize or ignore their difficulties by depicting autism only as a difference (e.g., "Différence neurologique/cérébrale," "Différence").

Je suis CONTRE le fait de présenter l'autisme comme juste une différence (c'est une différence ET un handicap, toujours).

I am AGAINST presenting autism as just a difference (it is a difference AND a disability, always).

# Use simple terms

This theme reflects participants' explanations for the use of terms that are simple and to the point such as "Personne autiste" and "Autiste," rather than "Personne avec autisme" or "Personne appartenant au spectre de l'autisme," which are perceived as wordy and convoluted.

J'aime utiliser le terme "Autiste" car il est clair et circoncis. Simple et efficace.

I like to use the term "Autistic" because it is clear and concise. Simple and efficient.

# Use precise terms

This theme reflects participants' viewpoint that we should use precise and accurate terms when talking about autism. Participants highlighted that "Personne neurodivergente" is not synonymous with "Personne autiste." That is, the meaning of neurodivergent is (too) broad and encompasses more diagnoses than just autism. According to these participants, it is appropriate to use this term to talk about a person if they have additional diagnoses (e.g., attention-deficit/hyperactivity

disorder [ADHD]), but if you want to refer to an autistic person specifically, "neurodivergent person" is not accurate enough and "autistic/autistic person" is preferred.

Likewise, participants insisted that "neurotypical" should only be used when the person had no other co-occurring conditions. If the person is not autistic but has another diagnosis, "Personne non-autiste" or "Personne allistique" were considered more accurate.

Pour ce qui est de personne neurodivergente ou personne neuroatypique pour moi le terme est trop vague. Si on parle que de personne autiste, alors autant dire le terme, si on parle disons de deux personnes autistes, une personne avec un TDAH et une personne schizophrène là oui ce terme est approprié.

As for the term neurodivergent person or neuroatypical person, for me the term is too vague. If we're talking about an autistic person, then we might as well use the term, but if we're talking about two autistic people, a person with ADHD and a schizophrenic person, then yes, the term is appropriate.

"Neurodivergent" renvoie pour moi à une catégorie plus large que "autiste", et "neurotypique" à une catégorie plus restrictive que "non-autiste" [sic].

"Neurodivergent" to me refers to a broader category than "autistic", and "neurotypical" to a more restrictive category than "non-autistic."

### Use validated terms

This theme encapsulates participants' preferences for terms that are clinically valid such as "Autisme" and "Trouble du Spectre de l'Autisme." In addition to disliking "Syndrome d'Asperger" due to negative connotations and implied hierarchy, participants also reported that they disliked this term because it lacks clinical validity as it is no longer a diagnostic category within the DSM-5.

J'exècre par-dessus tout l'appellation Asperger/syndrome d'Asperger. Je trouve que c'est une honte absolue que ce terme soit encore utilisé, même par certain [sic] médecins et professionnels de santé, d'une part vu les abominations auxquelles le terme fait référence, et aussi un peu parce que ce diagnostic n'existe tout simplement plus dans les classifications actuelles. Il est purement insultant, honteux, dépassé, désuet et discriminatoire. Pour moi cela est une réelle insulte quand quelqu'un me qualifie de la sorte.

I abhor the term Asperger/Asperger's Syndrome above all else. I find it an absolute disgrace that this term is still used, even by some doctors and health professionals, on the one hand because of the abominations to which the term refers, and on the other hand because this diagnosis simply doesn't exist anymore in the current classification. It is purely insulting, shameful, outdated and discriminatory. For me it is a real insult when someone calls me that.

# **Discussion**

The current study is the first to investigate the language preferences of French-speaking autistic adults across multiple countries. Our results indicate that the most preferred terms of French-speaking autistic adults (formally diagnosed and self-identified) were "Autisme" (*Autism*), "Personne autiste" (*Au-*

tistic person), "Autiste" (Autistic), "Est Autiste" (Is Autistic), "Différence neurologique/cérébrale" (Neurological/brain difference), "Différences" (Differences), "Difficultés" (Difficulties), "Personne neurotypique" (Neurotypical person), "Neurotypique" (Neurotypical), and "Personne non-autiste" (Non-autistic person).

These results confirm our hypotheses and converge with those of the existing literature, suggesting a preference for terms that reflect the ideas of IFL (e.g., "Est Autiste," "Personne autiste," "Autiste") and the social model of disability (e.g., "Différence," "Difficultés," "Handicap" [Disability]). Further, overall, participants disliked PFL (e.g., "Personne avec autisme," [Person with autism]) and medical terms (e.g., "Maladie" [Disease], "Trouble" [Disorder]).

This study also extends previous findings<sup>3,4,12</sup> by providing new insights into the reasons underlying autism-related language preferences. Indeed, across both the quantitative and qualitative data, there was a preference for terms that are *simple* and *precise*. Specifically, in addition to liking terms such as "Personne autiste," "Autiste," and "Est Autiste" because they express autism as an inherent attribute to who they are, participants also like these terms because they are simple and to the point.

Likewise, just as it is important not to beat around the bush when talking about autism, autistic people, and autistic identity, it is equally important to be precise, avoiding terms that are too broad (e.g., "Personne neurodivergent e" [Neurodivergent person]) or too narrow (e.g., "Personne neurotypique").

Further, despite the popularity of "Autiste" in the quantitative responses, the theme *Importance of context* highlighted an important degree of nuance. The use of "Autiste" as a noun (e.g., "un·e autiste," *an autistic*) is only liked when employed by other autistic people but not by non-autistic people. This finding is in line with previous research that has found that the term "autistic" is polarizing as it can carry negative connotations and can be misused by non-autistic people. 4.27 Likewise, context plays a role in participants' preferences in how they conceptualize autism more broadly: Many respondents highlighted that impairments are not necessarily inherent to autism (e.g., "Trouble"), but they rather arise as a result of being placed within the context of a disabling society (e.g., "Handicap"), in line with the social model of disability.

Participants also explained preferring terms that were clinically valid. This theme is particularly helpful in interpreting the surprising result that both "Trouble du Spectre de l'Autisme" (*Autism Spectrum Disorder*) and "Trouble" were more preferred than "Condition du Spectre de l'Autisme" (*Autism Spectrum Condition*) and "Condition" (*Condition*), respectively.

This is interesting since Aut'Créatif, <sup>28</sup> a Quebec-based movement of autistic people for the positive recognition of autism, recommend using the term "Condition" instead of "Trouble." "Condition du Spectre de l'Autisme" could have been perceived as lacking clinical validity, as it is not part of the DSM-5 whereas "Trouble du Spectre de l'Autisme" is. Although not mentioned explicitly in the comments, this explanation is plausible since participants reported that they disliked the term "Syndrome d'Asperger" (Asperger's Syndrome) for precisely this reason.

Another explanation for our results could lie in the translation process from English to French. Indeed, most (if not all) of the terms used to talk about autism in French initially come from English, and subtle nuances in meaning as well as differences in frequency may exist between English words and their French translations. For example, in French, "Condition" is mostly used in the sense of "circumstance" or "situation" (e.g., "conditions de la femme dans la recherche," status of women in research), and it is not commonly used to refer to disabilities/diagnosis such as autism, whereas this is the case for "Trouble."

This difference in meaning is less strong in English, where both words can be used to describe disabilities such as autism. Indeed, contrary to us, Keating et al<sup>27</sup> found that English-speaking participants preferred the term "Condition" (46.3%) over "Disorder" (33.6%).

Finally, both the quantitative and qualitative results high-lighted a dislike for terms that establish a hierarchy between autistic and non-autistic people (e.g., "Déficiences" (Impairments), "Performance plus faible/meilleure" (Poorer/better performance) or among autistic individuals themselves. With respect to the latter, participants felt that functioning label descriptors and "Syndrome d'Asperger" (and its derivatives) unnecessarily differentiate between autistic people who are all part of the same spectrum.

Further, the term "Syndrome d'Asperger" was disliked due to the negative connotations associated with its history. In line with this, the autistic participants eschewed other terms that disseminate negative connotations about autism, autistic identity, and the needs and abilities of autistic people (e.g., "Maladie," "Déficiences").

Overall, we found very similar trends to a parallel study by Keating et al.<sup>27</sup> English-speaking autistic adults showed a high endorsement of the English-equivalent terms for "Autisme," "Personne autiste," "Est Autiste/Asperger," "Différence neurologique/cérébrale," "Difficultés," "Différences," "Personnes neurotypiques," and "Neurotypiques." However, there were a few interesting cross-linguistic differences. "Personne neurodivergente" and "Est neurodivergent" were less endorsed by French-speaking adults (46.77% and 45.29%, respectively) than English-speaking autistic adults ("Neurodivergent person": 70% and "Is neurodivergent": 68.8%). This difference could be due to differences in frequency, with "neurodivergent" being a translation of English and introduced relatively recently in French.

Another cross-linguistic difference was observed for "Défis." In our sample, this term was only endorsed by a third of our participants, whereas the English-speaking equivalent "Challenges" was highly endorsed by participants (76.3%), on par with terms such as "Differences" and "Difficulties." This is likely due to a different connotation of that word in French; "Défis" mainly has a positive sense of challenge (like challenging oneself to run a marathon), leading to a personal accomplishment.

Finally, "A un diagnostic d'autisme" received higher endorsement than the English equivalent "Has a diagnosis of autism" (61.37% vs. 37.9%, respectively). Conversely, "A de l'autisme" received less endorsement than the English-equivalent "Has autism" (6.28% vs. 39.1%, respectively). This could be due to a stronger preference from French-speaking participants than English-speaking participants for clinically validated terms.

Interestingly, similar themes were identified in our qualitative analysis and the thematic analysis performed by Keating et al:<sup>27</sup> the idea that autism is inherent, the need to be concise, accurate, and specific when talking about autism, and the simplicity of the chosen terms. Taken together, this article highlights both similarities and differences between the preferences of English-speaking and French-speaking autistic adults, emphasizing the importance of studying linguistic preferences across languages as well as the usefulness of qualitative analyses to further understand these preferences.

There are several limitations to the current study. Firstly, the reported preferences are not representative of all autistic individuals as our sample did not include children or adolescents, and formal diagnoses, while consistent with other language preferences studies,  $^{4,27}$  typically occurred in adulthood ( $M_{\rm age\ of\ diagnosis} = 28.91$ ). Although our data are taken from individuals with a range of ages of diagnosis (2–68 years), recent evidence suggests that later diagnosed individuals may find IFL less offensive.

Thus, when producing autism-related language guidelines, it is important to consider potential differences in preferences that might accompany earlier or later diagnoses. In addition, we did not make specific adaptations to our questionnaire for non-speaking people or people with intellectual difficulties, so we do not know to what extent their opinions are represented in our data.

Second, our study was conducted entirely online, resulting in a self-selecting recruitment method for our sample (i.e., participants who have access to Internet and a computer). Requiring tech access may have also introduced a recruitment bias in favor of participants with a higher socioeconomic status (the average post-secondary years of education in our sample was 4.12 years). Participants who responded to the advertisements and completed the questionnaire may be interested in the debate regarding language to talk about autism.

We had very few respondents (N=3) who explicitly said that they did not care about the language used to talk about autism. Thus, our sample may be more representative of the online autistic, pro-neurodiversity community. In addition, the sex ratio in our study was one male participant for four female participants. Although this is the exact opposite of the prevalence historically reported in the literature,  $^{39,40}$  a recent mathematical model developed to quantify gender biases in diagnosis demonstrates that the true ratio may be closer to 3:4.

Moreover, although 74.1% of our sample responded that their sex assigned at birth was female and 22.4% male, only 38.6% of our sample responded that they identify as cisgender female and 13.7% cisgender male. Overall, 11.9% of our participants responded they were transgender and 30.3% said that they were non-binary. This high proportion of gender expansive responses<sup>b</sup> (42.2%) in our sample supports previous findings in the literature that compared with neurotypical people, autistic people are more likely to be gender-expansive. 42–45

<sup>&</sup>lt;sup>b</sup>Gender-expansive is an adjective that can describe someone with a more flexible gender identity than might be associated with a typical gender binary.

Although this demographic distribution highlights the importance of considering gender expansive identities in autism, our findings may represent a higher proportion of autistic individuals assigned female at birth. We are conscious that these results do not represent the views of all autistic people.

This study does not aim at delivering sweeping conclusions about the language preferences of autistic people, but to highlight some of them. We encourage future studies to develop new methods to include as many autistic people as possible, regardless of their computer access or their intellectual and language abilities.

Finally, it was beyond the scope of the current study to compare differences in autism-related language preference between the different French-speaking countries (with the majority of our sample residing in France or Belgium), and very little scientific research has examined differences in how autism is viewed across these countries. One exception is the work by Chamak, <sup>46</sup> which discusses the relative dominance of the biomedical model in France compared with Anglo-Saxon countries alongside the rise of neurodiversity.

Thus, an important consideration for future research is to examine social and ideological differences that may feed into differences in French-speaking language preferences across countries.

# Conclusion

This study is the first to investigate autism-related language preferences in a French-speaking sample of autistic adults (formally diagnosed and self-identified). Consistent with previous findings in English-speaking countries, most French-speaking autistic adults preferred terms in line with the social model of disability such as differences, difficulties, and disability.

Further, they preferred to talk about a person with a diagnosis using terms in line with the ideas of IFL, that is, linguistic expressions that conveyed autism as an inherent part of their personhood (e.g., autistic person, is autistic). Extending previous findings, this study also provided novel insight into the reasons underlying these preferences. Many French-speaking autistic adults disliked terms that conveyed a sense of hierarchy (among the autistic community and between autistic people and neurotypical people, e.g., Aspie, deficits) as well as terms that are not scientifically valid and not precise enough (e.g., Asperger Syndrome, neurodivergent).

This study highlights the importance of thinking about the words we use to most accurately reflect the experiences of autistic people. Although it remains crucial to prioritize individual preferences, this study provides a good basis for understanding the general preferences of French-speaking autistic adults.

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# **Authorship Confirmation Statement**

S.S., C.T.K., and L.H. designed the original questionnaire in English. P.G., F.P., M.B., and E.C. translated the ques-

tionnaire in French and collected the data. P.G. conducted the data analysis. P.G. drafted the article. F.P., M.B., E.C., L.H., C.T.K., and S.S. reviewed the draft and contributed to editing the final document. M.B. and E.C. contributed equally and have the right to list their name first in their CV. C.T.K. and S.S. contributed equally as senior authors and have the right to list their name last in their CV. All authors approved the final version. This article has been submitted solely to this journal and is not published, in press, or submitted elsewhere.

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# **Supplementary Material**

Supplementary Data SA

Supplementary Data SB

Supplementary Data SC

Supplementary Data SD

Supplementary Data SE

Supplementary Data SF

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Address correspondence to:
Philippine Geelhand
ACTE at LaDisco and ULB Neuroscience Institute
Université libre de Bruxelles
Avenue F.D. Roosevelt, 50/175
1050 Brussels
Belgium

Email: philippine.geelhand.de.merxem@ulb.be

# **Appendix**

# APPENDIX TABLE A1. THEMES IDENTIFIED IN THE OPEN-ENDED COMMENTS

Autism is inherent	Importance of context	Negative history and connotations	Problems of hierarchy
Terms that convey that autism is part of the person's identity	Terms that are preferred/disliked depending on the context of use	Terms that are associated with negative meanings such as historical contexts, stereotypes, insults, and stigma	Terms that convey a hierarchy between non-autistic and/or among the autism community
Don't downplay our difficulties	Use simple terms	Use precise terms	Use validated terms
Terms that downplay difficulties or do not reflect accurately the needs of autistic people	Don't use terms that are wordy and convoluted	Use terms that describe accurately the person /disability (ie., use of terms that are not too narrow and /or not too broad)	Use of terms that are clinically valid