



# Do Different Kinds of Minds Need Different Kinds of Services? Qualitative Results from a Mixed-Method Survey of Service Preferences of Autistic Adults and Parents

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**Abstract** Many services can assist autistic people, such as early intervention, vocational services, or support groups. Scholars and activists debate whether such services should be autism-specific or more general/inclusive/mainstream. This debate rests on not only clinical reasoning, but also ethical and social reasoning about values and practicalities of diversity and inclusion. This paper presents qualitative results from a mixed-methods study. An online survey asked autistic adults and parents of autistic people of any age in Canada, the United States, Italy, France, and Germany what types of services they prefer (autism-specific, mixed-disability, or general/inclusive/

mainstream). This paper presents the advantages and disadvantages of different service types, identified through inductive thematic coding and organized into higher-level themes focusing on clinical, structural, societal, interpersonal, and personal aspects of services. Autism-specific services were praised for addressing autism needs, helping clinically, and providing interpersonal benefits of others understanding autism; general services were praised for inclusion, helping clinically, community obligations and awareness, and social skills development. Looking at the interaction of these different aspects in respondent narratives nuances debates about autism-specificity, with a complex interplay between clinical, interpersonal, and societal aspects. Clinical and social perspectives are not necessarily separate and opposed, but intertwined based on different understandings of inclusion. Compared to parents, adults focused more on harm/safety issues, enjoyment, and stereotyping among other themes, attending to personal themes. These findings do not identify one best service type, but suggest that determining the right service in a given context may be informed by definitions of and goals about inclusion.

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## Introduction

Autism services raise important ethical questions about inclusion and neurological diversity. Neuroethics is well-poised to address such important ethical questions related to autism and the social world. Autism is often understood in neurological terms as a neurodevelopmental disorder in diagnostic guidelines [1] or more colloquially as a “different kind of mind” [2]. This perspective raises the following question: if autism is understood as a “different kind of mind,” what are the implications of that difference? Should different kinds of minds be encouraged to share service spaces, or should each kind of mind have a dedicated space? Determining how to organize services is both a clinical question and an ethical question. Clinically, researchers may ask which environment is most effective. Indeed, several studies have done so, particularly in the case of inclusive education, but have yielded mixed results [3–10]. These debates may take on a different shape and tenor in different contexts around the globe, where prevalence of autism, structure of educational, medical, and social services, and ideas about autistic ways of being in the world vary [11, 12]. Ethically, the structuring of these environments relates to major questions about the best and most just way to organize a neurologically diverse society and promote human flourishing [13, 14].

Scholars and advocates debate how to best support autistic people.<sup>1</sup> Many advocates, including parents/guardians, professionals, and autistic people, argue for autism-specific services and environments on the basis that they best serve the unique needs and strengths of autistic people. In doing so, they create and support communities of (perhaps literally) like-minded folks or allow autistic people to flourish without the pressures of a neurotypical (non-autistic) society [16–18]. Other advocates make strong arguments for non-diagnostic specific services in many settings and places, including education (e.g., inclusive education in the US, *integrazione scolastica* in Italy, mainstreaming in the UK), healthcare (e.g., autism as a form of “mental suffering” in Brazil, see [19]), recreation (e.g., unified sports teams), and housing (e.g.,

deinstitutionalization). Even participants in autism-specific services, such as some youth described in a study in Italy [20], sometimes express ambivalence, questioning the need for a focus on autism in services and questioning the need for their own continued engagement in autism-specific services after achieving specific goals. Advocates have also raised concerns that within the autism-specific framework, some settings are still too isolating. Some people argue that calls for autism-specific or disability-specific residential settings represent “neo institutions” [21, 22]. Others, such as the parent-led organization VOR (formerly Voices of the Retarded), argue that “disability-specific settings might be the most appropriate and least restrictive setting in which to serve particular people with disabilities” [23]. However, organizations led by disabled people reject this call for institutionalization and are generally at odds with organizations like VOR [23].

These debates demonstrate important ethical and social tensions around diagnostic-specificity in services, including autism-specificity. These multifaceted tensions include both clinical questions about what is most effective for accomplishing a specific medical, educational, or social “outcome” and ethical questions about the most just way to organize society and services. This paper aims to unpack the different considerations respondents bring to these debates. It reports the results of a mixed-methods survey asking autistic adults and parents/guardians of autistic people about their experiences with, and preferences for, services that are autism-specific or not. In a closed-ended question asking respondents if they overall preferred services that were autism-specific, mixed-disability, general, or if they preferred different types for different services, most respondents (both autistic adults and parents/guardians of autistic people) preferred autism-specific services overall, but almost as many reported “I prefer different types for different services” [24]. This paper follows up on that finding and adds qualitative nuance, addressing the question: What are the advantages and disadvantages of general, mixed-disability, and autism-specific settings, according to people who access these services? Inductive thematic analysis of open-ended survey responses identifies commonly mentioned advantages and disadvantages of services and organizes them into higher-level themes focusing on clinical, interpersonal, personal, structural, and societal

<sup>1</sup> In this paper, we primarily use identity-first language, in keeping with suggested practices for avoiding ableist language [15]

aspects of services. Autism-specific services were praised for addressing autism needs, helping clinically, and providing interpersonal benefits of others understanding autism, while general services were praised for promoting inclusion, community obligations and awareness, and social skills development. It may initially appear that autism-specific services are better, primarily from a clinical perspective, and general services are better primarily from a societal perspective. However, we argue that these aspects are not necessarily separate and opposed but rather intertwined based on different understandings of inclusion. The broader discourse is informed by structural accessibility concerns and under-recognized personal concerns of autistic adults.

## Methods

### Researcher Positionality Statement

Cascio worked on this project as a postdoctoral researcher in ethics at the Pragmatic Health Ethics Research Unit of the Institut de recherches cliniques de Montréal after completing dissertation research in anthropology that involved Italian autistic people, families, and professionals. Cascio's interest in this topic stems from a broader research program investigating identities and subjectivities related to the concept of autism from critical and cross-cultural perspectives. Racine is a bioethicist and academic researcher trained in humanities and social sciences and engaged in the development of qualitative, participatory, and deliberative research inspired by philosophical pragmatism. Racine's prior work has delved into various issues related to developmental conditions, such as cerebral palsy and fetal alcohol spectrum disorder, with the hope of bringing the lived experiences of persons into discussions about human flourishing. Neither researcher nor any other members of the research team identify as autistic or are diagnosed with autism. Autistic people, as well as parents/guardians of autistic people and academic readers were asked to provide feedback on the survey in each survey language. This feedback led to changes to questions, phrasing, and formatting when feasible.

### Survey Design

A detailed description of the survey design appears in another paper reporting on the quantitative analysis of the closed-ended questions in the same survey [24]. In brief, we developed a pair of online surveys (one for autistic adults and one for parents/guardians of autistic people of any age). The two respondent groups were independent and there is no way to tell if any autistic respondents' parents/guardians also responded. The surveys were available in English, French, Italian, and German and targeted participants in Canada, the United States, France, Italy, and Germany (cross-cultural differences will be the subject of a forthcoming paper). Both surveys included questions about demographic information, which types of services (e.g., early intervention, social/recreational services, support groups) respondents had used and in which categories (autism-specific, mixed-disability, or general), Likert scale ratings of how happy they were with services used, and overall which category of service they preferred. We defined autism-specific services as "made mostly for people with autism; most of the people who go there have autism; sometimes, the word autism is in the name." We defined mixed-disability services as "made for people with disabilities, diagnoses, or special education certificates; most of the people who go there have a disability, but not everyone has autism." We defined general services as "made mostly for people without disabilities but includes people with autism; sometimes called 'inclusive,' 'integrated,' or 'mainstream.'" The list of survey questions is available as supplementary material.

This paper focuses on the analysis of the open-ended responses. Open-ended survey questions asked respondents to elaborate on service use, evaluation, and overall preferences ("Please explain your answer"); list the advantages and disadvantages of each service category (e.g., "In your opinion, what are the advantages (good things) about autism-specific services"; "In your opinion, what are the disadvantages (bad things) about autism-specific services?") and provide final comments ("Is there anything else you would like the researchers to know?"). These questions were included in both versions of the survey.

## Recruitment & Data Collection

Data collection occurred online from April to November 2017. We emailed an invitation to share the survey and a reminder to services, associations, support groups, schools, and listservs identified online and through research team networks. We also posted the survey link on our academic social media. We sought to invite respondents accessing a wide range of service categories. However, due to the survey being about autism, autism-specific services are likely overrepresented (see limitations). Respondents could enter into a raffle for 100CAD gift cards to an online retailer. The Research Ethics Committee of the Institut de recherches cliniques de Montréal approved this study, and respondents provided informed consent online.

## Data Analysis

We applied thematic analysis to open-ended responses, assisted by Dedoose Qualitative Data Analysis Software [25]. First, we used an iterative-inductive process [26] to develop a codebook (Table 1). Two team members (coders) began by open-coding [27] a subset of English-language responses. Each coder read the same responses, and independently developed a list of codes guided by theoretical interest in advantages and disadvantages of different service categories, reasoning discourses, and values about inclusion and specificity, but also allowing for emergent themes. The coders, in conversation with the senior author, organized these open codes into a list of themes with definitions. The coders then repeated this process with another subset of English-language responses guided by the preliminary theme list, expanding and revising as necessary. When no new themes emerged, the team approved the final codebook. The coders then coded or recoded the same set of English and Italian data, still working independently to label passages with one or more appropriate codes from the codebook following the established definitions. They then compared each coders' code applications and discussed discrepancies, with the senior author serving as an arbitrator for any disagreements. The coders repeated this process for another round. After this round, over 80% intercoder consensus was established, and the remainder of the responses were coded by only one coder. Both coders were proficient in English and Italian. One coder was

proficient in French, and the other in German; data was coded in these languages accordingly. Between both groups (autistic adults and parents/guardians), 372 respondents took the survey in English, 189 in French, 72 in Italian, and 203 in German (Table 2). The team discussed points of uncertainty in coding and made minor changes to the codebook throughout the process, going back to recode previously coded texts to account for these changes.

We identified five overarching themes: clinical, interpersonal, personal, structural, and societal aspects. Given our interest in debates over specificity and inclusion, we also coded themes of values about specificity and values about diversity and inclusion. We describe describes several relevant subthemes in the results section. In this paper, we have chosen to report frequency counts of subthemes. Frequency counts guide our interpretation to important thematic areas, highlighting common themes, as well as important contrasts (between different service categories or different respondent groups), sometimes revealed by low frequency or absence [28]. Most of the subthemes were coded dichotomously, i.e., “staff preparedness (good)” vs. “staff preparedness (poor),” “enjoyed the service (good)” vs. “did not enjoy the service (poor).” We therefore compared the number of instances of the “good” version of subtheme to the number of instances of the “poor” version to determine the ratio. We classified ratios between 0 and 0.4 as primarily disadvantages, ratios between 0.4 and 0.6 as contested, and ratios between 0.6 and 1 as primarily advantages. This classification guides the presentation in Tables S3-S5 below and directs our interpretation towards potentially meaningful areas. It should not be taken as a definitive ranking of respondent priorities, but rather as a tentative overview of key areas of interest to respondents, as well as contrasts in those interests.

## Results

Surveys were completed by 704 parents/guardians and 132 autistic people. Demographics are presented (Table 2) for parents/guardians, parent/guardian's eldest child (87.9% of parents/guardians reported having only one child with autism), and autistic adults. Most autistic adults did not have an individualized education plan in school, whereas most autistic people

**Table 1** Codebook

Themes <i>Definition</i>	Subthemes	
<b>Clinical Aspects</b> <i>Content addresses issues in line with the reasoning of “evidence-based medicine” etc., such as a focus on evidence, outcomes, and knowledge base</i>	Academic skills development (good)	Academic skills development (poor)
	Community awareness (good)	Community awareness (poor)
	Helped (in general) (good)	Didn't help (in general) (poor)
	Learned about syndrome or symptoms (good)	Did not learn about syndrome of symptoms (poor)
	Life skills development (good)	Life skills development (poor)
	Outcomes for behavior (good)	Outcomes for behavior (poor)
	Outcomes for communication (good)	Outcomes for communication (poor)
	Outcomes for motor difficulties (good)	Outcomes for motor difficulties (poor)
	Outcomes for sensory issues (good)	Outcomes for sensory issues (poor)
	Scientific merit (good)	Scientific merit (poor)
	Social skills development (good)	Social skills development (poor)
	Staff preparedness (good)	Staff preparedness (poor)
		Caused harm/safety concerns
<b>Interpersonal Aspects</b> <i>Content addresses interpersonal social issues such as relationships with staff and others</i>	Others understand autism (good)	Others do not understand autism (poor)
	Others understand unique individual (good)	Others do not understand unique individual (poor)
	Relationship with other autistic attendees (good)	Relationship with other autistic attendees (poor)
	Relationship with other non-autistic attendees (good)	Relationship with other non-autistic attendees (poor)
	Relationship with other parents (good)	Relationship with other parents (poor)
	Relationship with others, unspecified (good)	Relationship with others, unspecified (poor)
	Relationship with staff (good)	Relationship with staff (poor)
<b>Personal Aspects</b> <i>Content addresses issues related to intrapersonal issues of how respondents report feeling about services</i>	Authenticity (good)	Authenticity (poor)
	Comfort (good)	Comfort (poor)
	Enjoyed the service (good)	Did not enjoy the service (poor)
	Respect (good)	Respect (poor)
<b>Societal Aspects</b> <i>Content addresses societal-level issues about groups or populations, regarding inclusion, diversity, and stereotypes. These are issues about how people relate to each other as members of a community in everyday contexts, beyond policy or legal obligations</i>	Advocacy (lack of burden)	Advocacy (burden)
	Advocacy (opportunity)	Advocacy (lack of opportunity)
	Community obligations (good)	Community obligations (poor)
	Lack of stigma (good)	Stigma (poor)
	Resist stereotypes (good)	Face stereotyping by others (bad)
	Quality of diversity (good)	Quality of diversity (poor)
	Quality of inclusion (good)	Quality of inclusion (poor)
<b>Structural Aspects</b> <i>Content addresses issues that are structural (e.g., political, socioeconomic, legal, policy, etc.) related to access, resources, money, and the State</i>	Demographics and Intersectionality	
	Accessibility of services (good)	Accessibility of services (poor)
<b>Values about specificity</b> <i>Content addresses the importance, or lack thereof, of autism specificity</i>	Accessibility within services (good)	Accessibility within services (poor)
	Addresses autism needs	Does not address autism needs
<b>Values about inclusion and diversity</b> <i>Content addresses the importance of inclusion and diversity</i>	Addresses non-autism needs	Does not address non-autism needs
	Individualization (good)	Individualization (poor)
	Inclusion is valued by the respondent	
	Diversity is valued by the respondent	
	Values similarity	

described by parents/guardians did. In both groups, common diagnoses were autism spectrum disorder, autism or autistic disorder, and Asperger's syndrome,

the latter common to over 80% of the autistic adult respondents. The majority of respondents were majority-ethnicity within their country and Christian

**Table 2** Respondent Demographics

Variable	Autistic Adults (N = 132)	Parent/ Guardians (N = 699)*	Parent/guardian's eld- est child with autism (N = 699)*
<b>Response Language</b>			
English	52 (39.4%)	316 (45.2%)	-
French	16 (12.1%)	172 (24.6%)	-
Italian	1 (0.8%)	71 (10.2%)	-
German	63 (47.7%)	140 (20.0%)	-
<b>Sex</b>			
Female	59 (44.7%)	618 (88.4%)	133 (18.9%)
Male	71 (53.8%)	76 (10.9%)	562 (80.4%)
Other	2 (1.5%)	0.0%	1 (0.1%)
Did not answer	0 (0.0%)	5 (0.7%)	3 (0.4%)
<b>Age</b>			
Mean (SD)	37.20 (12.13)	44.77 (8.79)	13.52 (7.91)
Range	18–66	25–81	2–86
Did not answer	5 (3.8%)	27 (3.8%)	11 (1.6%)
<b>Ethnicity†</b>			
White, Italian, or German	123 (93.2%)	580 (83.0%)	593 (84.3%)
Non-White, -Italian, or -German	10 (7.6%)	66 (9.4%)	84 (11.9%)
Other	10 (7.6%)	59 (8.4%)	61 (8.8%)
Did not answer	1 (0.8%)	25 (3.6%)	23 (3.3%)
<b>Religion†</b>			
Christian	49 (39.4%)	385 (54.6%)	-
Atheist/Agnostic	60 (45.4%)	167 (23.8%)	-
Other	26 (19.8%)	90 (12.6%)	-
Did not answer	7 (5.3%)	77 (10.9%)	-
<b>Diagnosis†</b>			
Autism Spectrum Disorder	40 (30.3%)	-	397 (56.4%)
Autism or Autistic Disorder	14 (10.6%)	-	136 (19.3%)
Asperger's Syndrome	107 (81.1%)	-	191 (27.1%)
Pervasive Developmental Disorder	2 (1.5%)	-	60 (8.5%)
Pervasive Developmental Disorder–Not Otherwise Specified	2 (1.5%)	-	55 (7.8%)
Atypical Autism	2 (1.5%)	-	28 (4.0%)
Other Diagnosis (Rett, Fragile X, Multiple Complex Developmental Disorder)	0	-	12 (1.8%)
Self-Diagnosis	11 (8.3%)	-	1 (0.1%) by child 5 (0.7%) by parent
Refused	0	-	3 (0.4%)
Other	0	-	29 (4.1%)
Don't know	2 (1.5%)	-	3 (0.4%)
<b>IEP</b>			
Yes	31 (23.5%)	-	514 (73.5%)
No	92 (69.7%)	-	143 (20.5%)
I don't know	8 (6.1%)	-	29 (4.1%)
Don't want to answer	1 (0.8%)	-	13 (1.9%)

**Table 2** (continued)

Variable	Autistic Adults (N = 132)	Parent/ Guardians (N = 699)*	Parent/guardian's eldest child with autism (N = 699)*
Support Level			
(Mean Irange)	3.05 11–71	-	-
Did not answer	7 (5.3%)	-	-

Religion responses aggregated as follows: Christian (Catholic, Orthodox, Protestant, Other Christian), Atheist/Agnostic (Atheist, Agnostic), Other (Orthodox Jewish, Other Jewish, Mahayana Buddhist, Theravada Buddhist, Vajrayana Buddhist, Other Buddhist, Hindu, Other), Refused to Answer

*IEP* Individualized Education Plan, *PIP* plan d'intervention personnalis e, *PAP* un PAP Plan d'accompagnement personnalis e, *PPS* ou un projet personnalis e de scolarisation, *PEI* piano educativo individualizzato, *IBP* individualisierten Bildungsplan

\*Responses from 704 parents were included in the qualitative analysis. Five responses from parents were excluded from this table due to problems with certain demographic responses: one French respondent and three English respondents listed their first child's sex as "other" but then specified information for multiple children in a single response (e.g., "one male and one female"). One English respondent listed their child's demographics in lieu of their own

†More than one response could be selected

or atheist/agnostic. Respondents reported a variety of advantages and disadvantages with respect to different service categories, both in response to questions about the different services they had used and overall questions about advantages and disadvantages. The following sections describe attitudes and preferences towards autism-specific services, mixed-disability services, and general services. They highlight differences between different service categories, as well as between the responses of parents/guardians and autistic adults.

#### Attitudes and Preferences Toward Autism-specific Services

##### Themes

For autism-specific services, the most frequently mentioned advantages were within the following themes: clinical (staff preparedness, mentioned on 329 instances; helping in general, 290 instances), values about specificity (addressing autism needs, 219 instances), and interpersonal (good relationships with staff, 153 instances; others understanding autism, 152 instances). Respondents also identified several disadvantages of autism-specific services, most notably the structural subtheme of poor accessibility of these services (360 instances). Respondents frequently noted that services did not exist, were not covered by insurance, were too expensive, or were too far away. Less frequently, they reported other issues such as language barriers, as in one parent/guardian

in Canada who wrote, "Rett specific are always best, but always difficult in this province due to language barriers." Respondents criticized eligibility barriers linked to diagnosis, co-occurring conditions, level of support needs, and age (especially in adulthood). Many autistic adults noted things like, "Diagnose erst als Erwachsene erhalten [Diagnosis only received in adulthood]" in open-ended responses about whether or not they had access to services, or explained in more detail: "Again, I was diagnosed with autism at a very late age, so many of my accommodations and help that I could have gotten, I didn't receive or didn't receive specifically for autism." Other commonly mentioned disadvantages were the societal subtheme of poor quality of inclusion (96 instances) and the clinical subtheme of poor scientific merit (57 instances).

Some subthemes appeared as both advantages and disadvantages of autism-specific services. While respondents praised the accessibility within autism-specific services on 123 instances, they also decried poor accessibility within services on 187 instances. Good accessibility within services could derive from autism-specificity, for example when "services sont sp ecifiquement pour les besoins des personnes avec autisme [services are specifically for the needs of people with autism]" (Parent/Guardian) and "Sanno come interagire con le persone autistiche e sanno adeguare l'intervento [They know how to interact with people with autism and know how to adapt the interventions]" (Parent/Guardian). Respondents also mentioned specific positive

aspects such as “calming wait spaces, shorter waits” (Parent/Guardian), being “sensory-friendly” (Autistic Adult), and the ability to “mention things about eye contact, loud noises etc. and it not be ignored” (Autistic Adult). Poor accessibility within services included lack of funding within services, over-taxed staff or high staff turnover, not enough hours of service provided, or too much paperwork. Some respondents specified a lack of accessibility for autistic individuals outside the more specific demographic targeted (e.g., an autistic adult respondent explained, “Adult females with Aspergers-like autism are not the population that autism services exist for”).

The role of individualization within autism-specific services was particularly ambivalent across the total sample. Good individualization was listed as an advantage of such services 98 times, but poor individualization as a disadvantage 99 times. While many respondents simply reported that autism-specific services included good individualization, tailoring, or attention to the person’s individual needs and strengths, some connected this explicitly to the autism-specific nature of the service, for example, “Autism “treatments” can vary so widely, as can autism itself; autism-specific services recognize this and are able to apply or recommend the most appropriate services” (Parent/Guardian). Comments about poor individualization within autism services also address this variation, with some participants criticizing a “one approach serves all model” (Autistic Adult) and attempts to “bucket those with autism into the same categories” (Parent/Guardian). Respondents stressed that “no two autistics are alike” (Autistic Adult) and that “l’autisme est un spectre très large [autism is a very broad spectrum]” (Autistic Adult). Some worried that autism-specific services “don’t see the whole child – just the diagnosis” (Parent/Guardian) or otherwise give limited attention to individual-specific needs, such as the autistic adult who wrote:

There’s a lot of overlap between autism and other disabilities (especially the “cousins,” like ADHD, for example), and segregating based on diagnosis instead of what thing you specifically need help with sometimes limits your resources. Also, there tends to be greater

societal pressure to “fix people” in autism-specific services as opposed to people who are struggling without a particular diagnosis or with a diagnosis that’s less in the limelight.

Respondents also talked about encountering services that worked for some people with autism but not others, for example, services “geared toward more high functioning individuals” (Parent/Guardian) or, on the other hand, toward “other participants at lower level and not geared for my child” (Parent/Guardian).

### *Comparing Parents/Guardians and Autistic Adults*

Parents/guardians and autistic adults were generally in agreement with respect to the most frequently mentioned advantages of autism-specific services, but much less unified with respect to disadvantages (Table 3). Both respondent groups identified clinical subthemes (staff preparedness, helpfulness), values about specificity (addressing autism needs), and the interpersonal subtheme of others’ understanding autism primarily as advantages of autism-specific services. The only difference in the five most common advantages was that parents/guardians more frequently invoked the interpersonal subtheme of a good relationship with staff (e.g., “there’s a tenderness to people who decide to specialize in Autism—my child can feel the kindness of these people”) and autistic adults more frequently invoked the clinical subtheme of good social skills development (e.g., “Die Autis-musselbsthilfegruppen helfen mir, besser mit meinem Autismus und den Schwierigkeiten mit Nichtautisten klar zu kommen und sozialen Umgang zu haben. [The autism support groups help me to cope better with my autism and the difficulties getting along with non-autistic people, and to have social contacts]”).

Parents/guardians listed primarily as advantages several subthemes not primarily described this way by autistic adults, including values about specificity (individualization), the societal subtheme of community obligations, the personal subtheme of enjoying the service, interpersonal subthemes (relationships with other parents/guardians, good relationships with other attendees without autism) and the clinical subtheme of good outcomes for motor difficulties. Parents/guardians also listed poor individualization and poor community obligations as disadvantages, making these advantages contested. Adults listed

**Table 3** Themes regarding the advantages and disadvantages of autism-specific services (number of occurrences per theme)

Advantages				Disadvantages			
Parents	#	Adults	#	Parents	#	Adults	#
Staff preparedness	298	Staff preparedness	31	Accessibility of services	328	Accessibility of services	32
Helped (in general)	266	Others understand autism	27	Accessibility within services*	169	Individualization	26
Addresses autism needs	193	Addresses autism needs	26	Quality of inclusion	90	Caused harm/safety concerns	23
Relationship with staff	139	Helped (in general)	24	Individualization*	73	Accessibility within services*	18
Others understand autism	125	Social skills development	19	Scientific merit	53	Face stereotyping by others	13
Learned about syndrome or symptoms	114	Respect*	17	Community obligations*	46	Respect*	12
Accessibility within services*	110	Relationship with other autistic attendees	15	Face stereotyping by others	30	Problems getting diagnosis	12
Individualization*	87	Life skills development	15	Advocacy	24	Comfort*	10
Community obligations*	55	Relationship with staff	14	Comfort*	19	Relationship with other non-autistic attendees	7
Social skills development	50	Accessibility within services*	13	Quality of diversity	18	Quality of inclusion*	6
Enjoyed the service	47	Learned about syndrome or symptoms	13	Does not address non-autism needs	12	Did not enjoy the service	6
Outcomes for behavior	41	Comfort*	8	Others do not understand unique individual*	9	Community obligations	6
Life skills development	35	Others understand unique individual	7	Stigma	7	Advocacy (burden)	5
Relationship with other parents	32	Authenticity	7	Relationship with other non-autistic attendees *	3	Scientific merit*	4
Relationship with other autistic attendees	30	Quality of inclusion*	6	Outcomes for sensory issues	2	Does not address non-autism needs	4
Outcomes for communication	29	Scientific merit*	5			Relationship with other parents	3
Comfort*	28	Advocacy (opportunity)	5				
Academic skills development	28	Quality of diversity	4				
Relationship with others, unspecified	27	Outcomes for behavior	3				
Respect	21	Relationship with others, unspecified	3				
Advocacy (opportunity)	14	Academic skills development	2				
Community awareness	13	Community awareness	2				
Others understand unique individual*	12	Outcomes for communication	2				
Authenticity	9	Outcomes for sensory issues	2				
Outcomes for motor difficulties	3	Lack of stigma	1				
Relationship with other non-autistic attendees *	2						

*Black box* Respondents in this group mentioned this theme primarily as an advantage/disadvantage, while the other respondent group did not, *grey box* Respondents in on group contested this theme (see \*), while the other respondent group did not

\*Contested. Respondents mentioned this theme a similar number of times as an advantage and as a disadvantage (ratio advantage:disadvantage .4-.6)

primarily as advantages several subthemes not primarily described this way by parents/guardians, namely, the societal subthemes of quality of inclusion, quality of diversity, and a lack of stigma, and the clinical subthemes of scientific merit and outcomes for sensory issues. Parents/guardians and autistic adults both primarily listed respect as an advantage, but for adults this was also contested in that they almost as frequently listed lack of respect as a disadvantage. Similarly, both groups listed the subtheme of others understanding the unique individual as an advantage, but it was contested for parents/guardians

who also frequently listed poor understanding of unique individual as a disadvantage.

Parents/guardians and autistic adults were much less unified when it came to the disadvantages of autism-specific services. Both listed the structural subtheme of poor accessibility of such services most frequently and frequently noted poor individualization and accessibility within services. For adults with autism, individualization comments were primarily about poor individualization, but for parents/guardians, as mentioned above, it was contested. Parents/guardians were also more conflicted about community

obligations, whereas autistic adults listed it primarily as a disadvantage. On the other hand, autistic adults were conflicted about the quality of inclusion and scientific merit, whereas parents/guardians discussed these themes primarily as disadvantages.

Parents/guardians wrote about some features as disadvantages that autistic adults wrote about more as advantages, most notably the societal subtheme of quality of diversity, as well as presence/lack of stigma (also a societal subtheme) and the clinical subtheme of outcomes for sensory issues. Likewise, autistic adults listed several disadvantages that parents/guardians did not list or wrote about more as advantages, including clinical subthemes (harm/safety concerns, problems getting a diagnosis), personal subthemes (respect, enjoying the service or not), and the interpersonal subtheme of poor relationships with parents/guardians. Autistic adults' responses about services causing harm or raising safety concerns often focused on attitudes and approaches towards autism, including specific criticisms of Applied Behavior Analysis.<sup>2</sup> Two autistic adult respondents raised poor relationships with parents/guardians in autism-specific groups as a specific disadvantage of autism-specific services. One explained that autism-specific services "tend to be dominated by the point of view of parents/guardians, care givers and experts, rather than autistic people, and they often have different priorities than I do. So they may be very good at offering the services that they offer, but those aren't the services that I need. I tend to need help with accessibility (getting documentation, lobbying for it), while they tend to be good at social support for families."

#### Attitudes and Preferences Toward Mixed-disability Services

##### *Themes*

Advantages and disadvantages notably differed between autism-specific and mixed-disability

services. The top advantages of mixed-disability services were clinical (helped in general, 153 instances), societal (good quality of inclusion, 107 instances), and interpersonal (good relationships with staff, 104 instances). The top disadvantages were clinical (poor staff preparation, 235 instances; did not help, 124 instances), structural (accessibility within services, 207 instances; accessibility of services, 155 instances), and values about specificity (did not address autism needs, 146 instances; individualization, 91 instances). As these numbers suggest, responses were ambivalent about the subtheme of help (in general).

Inclusion, which was not a prominent advantage for autism-specific services (37 instances), was the second most common advantage listed for mixed-disability services (107 instances). A good quality of inclusion in mixed-disability services could mean that, "Kids with autism can see that there are other people with other disabilities. They are not alone" (Parent/Guardian). A mixed-disability service "gives greater interaction with people with varying conditions and allows a greater sense of empathy" (Autistic Adult). Even more broadly, "Ils peuvent reconnaître et intégrer plus facilement nos jeunes dans la société ! [They can recognize and more easily integrate our youth in society!]" (Parent/Guardian). Respondents wrote that mixed-disability services "Permette un po' a tutti l'integrazione e la tolleranza (nonostante le differenti disabilità) [allow a little bit of integration for everyone, and tolerance (despite the different disabilities)]" (Parent/Guardian). Some respondents did address how autism-specific services could foster inclusion, e.g., "They are with their "tribe" they get each other and don't feel weird or out of place" (Parent/Guardian). However, respondents more often described the inclusiveness of mixed-disability services and, as will be seen below, general services.

#### *Comparing Parents/Guardians and Autistic Adults*

Parents/guardians and autistic adults had comparable responses for both advantages and disadvantages of mixed-disability services. Both noted the clinical subtheme of helpfulness (though for parents/guardians, it was contested) and the societal subthemes of good quality of inclusion and good quality of diversity. Parents/guardians additionally raised the interpersonal subtheme of good relationships with the

<sup>2</sup> Applied behavior analysis is a form of therapy originating from operant conditioning principles and commonly recommended for autistic children. It involves an analysis of antecedents, behaviors, and consequences, and the implementation of various structured interventions aimed at behavior change. Self-advocates have criticized applied behavior analysis both for specific techniques (e.g., use of aversives) and general principles (e.g., pursuing "normal" appearances) [29].

**Table 4** Themes regarding the advantages and disadvantages of mixed-disability services (number of occurrences per theme)

Advantages				Disadvantages			
Parents	#	Adults	#	Parents	#	Adults	#
Helped (in general)*	133	Helped (in general)	20	Staff preparedness	213	Accessibility within services	23
Relationship with staff	99	Quality of inclusion	14	Accessibility within services	184	Staff preparedness	22
Quality of inclusion	93	Social skills development	12	Accessibility of services	139	Accessibility of services	16
Learned about syndrome or symptoms	80	Individualization*	10	Does not address autism needs	130	Does not address autism needs	16
Quality of diversity	78	Quality of diversity	10	Didn't help (in general)*	112	Individualization*	12
Social skills development	55	Learned about syndrome or symptoms	9	Individualization	79	Respect	11
Community obligations*	40	Life skills development	8	Others do not understand autism	41	Comfort	10
Community awareness	35	Academic skills development	6	Comfort	35	Face stereotyping by others	10
Relationship with other non-autistic attendees	35	Addresses non-autism needs	6	Community obligations*	33	Caused harm/safety concerns	10
Addresses non-autism needs	34	Relationship with staff	5	Outcomes for behavior	27	Others do not understand autism	6
Relationship with others, unspecified	33	Community awareness	4	Problems getting diagnosis	24	Community obligations	6
Outcomes for communication	31	Advocacy (opportunity)	4	Caused harm/safety concerns	24	Problems getting diagnosis	4
Enjoyed the service	25	Outcomes for communication	3	Advocacy (burden)	23	Did not enjoy the service	4
Life skills development	19	Others understand unique individual*	3	Scientific merit	23	Others do not understand unique individual*	2
Respect	17	Relationship with others, unspecified*	3	Face stereotyping by others*	14	Relationship with others, unspecified*	2
Outcomes for motor difficulties	17	Relationship with other autistic attendees	2	Academic skills development*	8	Relationship with other non-autistic attendees	2
Resist stereotypes*	15	Outcomes for behavior*	1	Others do not understand unique individual*	7	Advocacy (burden)	2
Academic skills development*	12	Outcomes for motor difficulties	1	Authenticity	3	Authenticity	2
Relationship with other parents	12	Lack of stigma	1			Scientific merit	2
Others understand unique individual*	10					Relationship with other parents	1
Advocacy (opportunity)	10					Outcomes for behavior*	1
Relationship with other autistic attendees	5						
Lack of stigma	5						
Outcomes for sensory issues	3						

*Black box* Respondents in this group mentioned this theme primarily as an advantage/disadvantage, while the other respondent group did not, *grey box* Respondents in one group contested this theme (see \*), while the other respondent group did not

\*Contested. Respondents mentioned this theme a similar number of times as an advantage and as a disadvantage (ratio advantage:disadvantage .4-.6)

staff and the clinical subtheme of learning about a syndrome or symptom as advantages. Autistic adults raised the clinical subtheme of good social skills development (e.g., “Man lernt neue Blickfelder kennen, wie ein Mensch mit einer anderen Behinderung zurechtkommt und lernt dadurch soziale Kompetenzen und Empathie. [You get to know new points of view, how a person can cope with a different disability and thereby learn social skills and empathy]”), as well as the value about specificity of individualization (although it was contested, and also appears in the list of top five disadvantages; for parents/guardians, poor individualization was only a disadvantage).

Parents/guardians and autistic adults had very similar perspectives on the disadvantages of

mixed-disability services, sharing four of the five most frequent subthemes: the clinical subtheme of poor staff preparedness, structural subthemes of poor accessibility both of and within services, and finding that services did not address autism needs. Parents/guardians additionally raised that the services did not help, and autistic adults raised that individualization within services was poor.

Parents/guardians discussed several features as advantages or as contested that autistic adults listed primarily as disadvantages, namely interpersonal subthemes (relationship with other non-autistic attendees, relationship with other parents/guardians), personal subthemes (enjoying the service, respect), the clinical subtheme of outcomes for sensory issues, and

societal subthemes (community obligations, stereotypes). Autistic adults wrote about individualization and outcomes for behavior as both advantages and disadvantages, which parents/guardians wrote about primarily as disadvantages (see Table 4). For relationships with non-autistic attendees, parents/guardians wrote about advantages like, “Avec le temps, je trouve que c’est plutôt positif car n’ayant pas les mêmes difficultés, les jeunes peuvent s’épauler. [With time, I’ve found that it is rather positive because, not having the same difficulties, the youth can support each other].” They wrote about both social interaction, e.g., “Social interaction with children of all abilities,” and social skills development, e.g., “the diversity is great and my son feels helpful towards those with more physical disabilities so he learns how to help others,” as advantages. Few autistic adults wrote about these relationships, but when they did it was primarily negative, e.g., “lack of acceptance for people with hidden/invisible disabilities such as autism even among other persons with disabilities; social problems of autistic people are just as great dealing with non-autistic people with disabilities as with non-disabled non-autistic people” and “Too-many non-disabled people (I don’t mean non-visibly disabled people, I mean parents and/or carers) that tend to talk over us.” Parents/guardians primarily reported that their children enjoyed mixed-disability services (e.g., “My children enjoyed the opportunity to attend camp and love special Olympics”), whereas autistic adults primarily reported that they did not (e.g., “Didn’t like school”, “Gruppen sind einfach nichts für mich [Groups are just not for me]”). For the subtheme of respect, parents/guardians wrote about advantages, e.g., “Everyone who has interacted with has treated my child with respect and never like there was something “wrong” with him” (Parent/Guardian). Autistic adults, on the other hand, wrote primarily about a lack of respect, e.g., “Insulting focused on the wrong skills.”

#### Attitudes and Preferences Towards General Services

##### *Themes*

General services had a different pattern of advantages and disadvantages, with the most cited advantage being societal (quality of inclusion, 206 instances) followed by the clinical subthemes of helpfulness

(147 instances) and social skills development (88 instances), the societal subtheme of community obligations (60 instances), and the clinical subtheme of community awareness (58 instances). The most mentioned disadvantages were the clinical subtheme of staff preparedness (228 instances), the structural subtheme of accessibility within services (175 instances), values about specificity subtheme does not address autism needs (97 instances), the interpersonal subtheme of others not understanding autism (94 instances), and the clinical subtheme of harm/safety concerns (53 instances). Respondents listed the subthemes of relationship with staff and accessibility of services commonly as both advantages and disadvantages.

Respondents wrote about general services promoting inclusion by allowing “vivre insieme agli altri, stessi diritti stessi doveri [living together with others, same rights, same responsibilities]” (Parent/Guardian) and engaging autistic people with peers in the same class, age group, or community. Many respondents wrote about inclusion “providing opportunities for typically-developed people to learn about people who have disabilities and/or special needs” (Parent/Guardian) or otherwise overlapping with the community awareness and/or community obligation subthemes. Responses stressed how autistic and non-autistic people sharing spaces can promote awareness of autism among non-autistic people and how this awareness can prompt community support, or how sharing space can promote openness even in the absence of increased awareness of medical models of autism (e.g., “l’inclusion est une arme idéale pour faire progresser l’individu handicapé en milieu ordinaire et l’[e]mpathie des neurotypiques pour les personnes handicapées [inclusion is an ideal tool for advancing disabled people in mainstream environments and advancing neurotypical people’s empathy for disabled people]” (Parent/Guardian). Other responses stressed the importance of inclusion as a reflection of community obligations aside from awareness, e.g., “Beaucoup d’autistes sont capables d’être inclus dans des services généraux (école ordinaire, centre de loisirs, activités culturelles et sportives...). Il suffit juste d’être ouvert d’esprit! [Many autistic people can be included in general services (mainstream schooling, recreation centers, cultural and sporting activities...). It just takes

an open mind!])” (Parent/Guardian). Respondents praised inclusion for “giv[ing] me a chance to be more than just disabled” (Autistic Adult), for benefiting self-esteem, for helping people “non sentirsi diversi [not feel different]” (Parent/Guardian) or “be social and also just be regular kids” (Parent/Guardian), and for allowing people to be exposed to more things, to be in “il ‘monde reale’ [the ‘real world’]” (Parent/Guardian), “un milieu dit normal [a so-called normal environment]” (Parent/Guardian) or “be seen as normal” (Parent/Guardian). Some respondents associated inclusion with good relationships with others, for example the parent who noted, “the world is made of all kinds of people and should not be segregated. Autistic individuals need to develop relationships and be able to interact with all kinds of people.”

While many of these quotes address inclusion in a societal way, good quality of inclusion also overlapped frequently with clinical subthemes of good social skills development (48 instances) and good outcomes for behavior (10 instances). As one parent/guardian explained, “Inclusion of neurotypical individuals is often useful if the personalities are a good match. These situations can be very helpful for modelling of standard social skills and exposure to a wider range of experiences.” In contrast, other parents/guardians valued inclusion specifically for the ability to medicalize less, as in the parent who explained “we can see the ‘gap’ instead of medical diagnosis. We can evaluate what symptoms/behaviours actually needs correction/modification. Some can be accepted as we learn to be inclusive.”

Finally, split responses about accessibility of general services stands out (48 instances of good accessibility, 101 instances of poor accessibility), in contrast to lack of accessibility of services as a major disadvantage of both autism-specific and mixed-disability services. Respondents sometimes noted that general services were more accessible than autism-specific or mixed-disability services, e.g., a “wider range of options are available when it is open to the mainstream” (Parent/Guardian). This advantage may be a begrudging one, as implied in the tone of one parent/guardian who wrote, “At least they’re available.” However, respondents still wrote about long waiting lists, high costs, lack of funding, and paperwork barriers for general services.

### *Comparing Parents/Guardians and Autistic Adults*

Parents/guardians and autistic adults had somewhat similar perspectives on the advantages of general services, though parents/guardians were more conflicted about the interpersonal subtheme of relationships with staff, and autistic adults were more conflicted about the clinical subtheme of whether the service helped (Table 5). Both reported good quality of inclusion and social skills development. Autistic adults wrote about enjoying the service and parents/guardians about the way the service demonstrated or contributed to community awareness. In terms of disadvantages, the two groups were also rather unified. Both groups wrote a lot about poor staff preparedness (a clinical sub-theme), poor accessibility within services (structural subtheme), and the services not addressing autism needs (value about specificity). Parents/guardians also wrote frequently about the interpersonal subtheme of others not understanding autism and the structural subtheme of poor accessibility of services, whereas adults wrote more frequently about services not helping (a clinical subtheme) and facing stereotypes by others (a societal subtheme), although both were contested (also written about as advantages).

Autistic adults wrote about stereotypes and accessibility of services as both disadvantages and advantages, whereas parents/guardians wrote about them primarily as disadvantages. Parents/guardians wrote about several other features as contested that autistic adults wrote about primarily as disadvantages: relationship with other attendees without autism, respect, relationships with unspecified others, and outcomes for sensory issues. Parents/guardians wrote about outcomes for behavior and motor difficulties primarily as advantages, whereas autistic adults did not write about these clinical aspects at all. In terms of disadvantages, autistic adults wrote about helping and community obligations as contested, whereas for parents/guardians, they were primarily advantages. Autistic adults wrote about poor relationships with unspecified others, whereas parents/guardians wrote about these relationships primarily as advantages. Parents/guardians wrote about a number of features as contested that autistic adults wrote about primarily as advantages, namely, relationships with staff, academic skills development, stigma, and authenticity, as well as outcomes for

**Table 5** Themes regarding the advantages and disadvantages of general services (number of occurrences per theme)

Advantages				Disadvantages			
Parents	#	Adults	#	Parents	#	Adults	#
Quality of inclusion	187	Helped (in general)*	24	Staff preparedness	199	Accessibility within services	30
Helped (in general)	123	Quality of inclusion	19	Accessibility within services	145	Staff preparedness	29
Relationship with staff*	77	Enjoyed the service	16	Others do not understand autism	80	Does not address autism needs	19
Social skills development	74	Social skills development	13	Does not address autism needs	78	Didn't help (in general)*	18
Community awareness	54	Relationship with staff	11	Accessibility of services	77	Face stereotyping by others*	14
Community obligations	54	Resist stereotypes*	10	Relationship with staff*	60	Accessibility of services*	14
Quality of diversity	48	Accessibility of services*	10	Caused harm/safety concerns	45	Others do not understand autism	14
Learned about syndrome or symptoms	35	Academic skills development	8	Comfort	35	Individualization	13
Relationship with other non-autistic attendees *	31	Learned about syndrome or symptoms	8	Individualization	34	Respect	9
Respect*	30	Community obligations*	6	Face stereotyping by others	32	Caused harm/safety concerns	8
Outcomes for behavior	27	Life skills development	6	Relationship with other non-autistic attendees *	28	Comfort	8
Enjoyed the service	27	Quality of diversity	5	Problems getting diagnosis	24	Relationship with others, unspecified	7
Relationship with others, unspecified*	23	Addresses non-autism needs	5	Respect*	23	Community obligations*	6
Life skills development	19	Outcomes for communication	4	Advocacy (burden)	21	Relationship with other non-autistic attendees	5
Academic skills development*	17	Relationship with other autistic attendees	4	Others do not understand unique individual	13	Others do not understand unique individual	4
Outcomes for communication	17	Lack of stigma	4	Academic skills development*	12	Advocacy (burden)	4
Addresses non-autism needs	13	Community awareness	4	Scientific merit	10	Problems getting diagnosis	2
Advocacy (opportunity)	11	Authenticity	2	Stigma*	6	Scientific merit	1
Outcomes for motor difficulties	9	Advocacy (opportunity)	2	Authenticity*	4		
Lack of stigma*	5			Outcomes for sensory issues*	2		
Authenticity*	4			Relationship with other parents	2		
Relationship with other autistic attendees	3						
Outcomes for sensory issues*	2						

*Black box* Respondents in this group mentioned this theme primarily as an advantage/disadvantage, while the other respondent group did not, *grey box* Respondents in one group contested this theme (see \*), while the other respondent group did not

\*Contested. Respondents mentioned this theme a similar number of times as an advantage and as a disadvantage (ratio advantage:disadvantage .4-.6)

sensory issues, which autistic people did not write about. Parents/guardians wrote about poor relationships with other parents/guardians, but autistic people did not address these relationships in the context of general services. In contrast to autism-specific services, for general services it was parents/guardians who more frequently raised harm/safety concerns, although autistic adults did as well. Concerns of harm and safety included harmful medications or overmedication; bullying, shunning, or “mobbing”<sup>3</sup>; injury or violence; neglect; trauma; or the possibility

that services would be counterproductive, causing new or worsening problems.

## Discussion

Various configurations of services are envisioned for autistic people, notably autism-specific and more general/inclusive/mainstream approaches. Like other healthcare choices and general orientations, beyond the medical sensu stricto, there are important ethical and social aspects at stake with respect to values and practicalities of diversity and inclusion. We undertook a mixed-methods online survey study in Canada, the United States, Italy, France, and Germany to better understand the preferences and experiences of

<sup>3</sup> This term is used in some European countries, in this sample often by German-speaking participants, to refer to a specific kind of bullying of an individual by a group, especially but not exclusively in the workplace [30].

autistic adults and parents/guardians of autistic people. While results from the quantitative analysis of this study [24] suggest that most participants do prefer autism-specific services overall, regardless of most demographics, many indicated that they prefer different categories of services (autism-specific, mixed-disability, or general) for different service types (school, vocational, support groups, etc.). The results of the qualitative analysis unpack some of the nuances of these preferences by highlighting the advantages and disadvantages of different service types, including several areas of complex interplay between different priorities.

Respondents praised autism-specific services for addressing autism needs, helping clinically, and providing the interpersonal benefits of others understanding autism, whereas they praised general services for inclusion, helping clinically, community obligations and awareness, and social skills development. They praised mixed-disability services for helping clinically and inclusion, as well as for good relationships with staff. Respondents criticized autism-specific services for poor accessibility, poor quality of inclusion, and concerns about their scientific merit, whereas they criticized general services for poor staff preparedness, poor accessibility, not understanding autism or addressing autism needs, and harm/safety concerns. They criticized mixed-disability services for poor staff preparation, accessibility, not addressing autism needs, and poor individualization. Several themes appeared more commonly in responses from autistic adults than from parents/guardians, including harm/safety issues, respect, enjoyment, and stereotyping. Unpacking these observations suggests that autism service preference is informed by complex intersections of clinical and non-clinical perspectives, that accessibility remains an overriding concern for services in general, and that autistic individuals' preferences may be overlooked when focusing on parent perspectives or combined samples.

#### Inclusion Rests at the Complex Intersection of the Clinical and Non-clinical

Respondents frequently discussed whether a service helped, in general or with respect to specific things, most commonly social skills, as well as life skills, academic skills, communication, behavior, motor difficulties, and sensory issues. Several clinical

perspectives inform service preference. Certainly, a clinical or (bio)medical model has been a dominant way of describing autism, especially in the research literature [31], but it is not the only way. Autistic self-advocates along with some parents/guardians and professionals have put forth models such as neurodiversity, which focuses on autism as a different way of being in the world [32] and has, in various contexts, been described as a social model of disability [33] or a biological citizenship model [34, 35]. These different understandings of autism – what it is and what autistic people need – may be opposed and yet may also overlap in individual and collective narratives [36–39]. It is therefore important to understand how different ways of thinking about autism, clinical and non-clinical, inform service preference.

Looking at the commonly mentioned advantages and disadvantages for each service type, it may initially appear that autism-specific services are better from a clinical perspective (and for the specific interpersonal goal of others understanding autism), and that general services are better from a societal perspective (and for the specific clinical goal of social skills development). However, looking at how these different factors interact in respondent narratives reveals nuance, especially with respect to the ambiguous position of “the social” within autism services, in which social interaction is often medicalized and medical intervention “Aspergerized” to attend to relationship building and play [39]. “Social skills” in particular are contested, and parents/guardians and autistic people may have different goals for social skills development, as in the respondent quotes reported above. Some respondents argue that autism-specific services facilitate inclusion through the clinical effort of promoting social skills development through autism-focused training. Other respondents argue that autism-specific services hinder inclusion by separating autistic people from others, appealing to societal aspects like community obligations and advocacy. This latter perspective values diversity over specificity. However, another perspective argues for mixed-disability or general services because that diversity may be valuable for clinical reasons. For example, it can provide opportunities for autistic people to practice social skills with non-autistic people. On the other hand, some respondents argue that inclusion is actually better accomplished in autism-specific spaces, not through social skills development

aimed at promoting neurotypical communication, but through freedom from the pressure to act neurotypically. These discussions reveal a complex intersection of themes related to social skills development, relationships with people with and without autism (social interaction), and community awareness (as people without autism learn more about autism through exposure to autistic people in these spaces). Sometimes, the onus is on autistic people to become more like non-autistic people (develop neurotypical social skills); other times, the onus is on non-autistic people to learn about autism and apply awareness and sensitivity to creating more accessible and inclusive spaces. These discussions debate not only which services best accomplish the goal of inclusion, but also how to define and understand inclusion in light of the diverging interests of different persons. They importantly reframe the conversation to consider inclusion from multiple viewpoints, suggesting that the ways that autism services can promote or inhibit inclusion depend on the definition of inclusion, which may hinge on different views about what is valuable and preferable.

#### Accessibility Concerns May Take Precedence over Preference

Our data suggest that service preferences are not nearly as important as the question of accessibility. The dominance of discourse on access is unsurprising in light of both literature and advocacy discourse. Research has repeatedly identified gaps in autism service provision. An estimated 1 in 8 children with autism in the United States have at least one unmet need such as medical care, specialist care, or mental health care [40]. In Canada, a needs assessment survey by the Canadian Autism Spectrum Disorders Alliance reported parent-identified unmet service needs including early intervention, employment or day programs, social skills programs, activity-based programs, and recreation programs and adult-identified needs including mental health treatment, employment services, social skills, post-secondary education, and housing/residential options [41]. Research on child and adolescent mental health services in Italy suggest the need to increase capacity to meet the needs of autistic people [42]. While it remains an open question if a given service is indeed appropriate or is designed

in an accessible way, the accessibility of services at all remains an important concern for respondents in all regions investigated in this study [43]. Our analysis suggests important differences in the accessibility of service categories, as respondents weighed accessibility against other advantages and disadvantages differently, with poor accessibility being the most common criticism for autism-specific services, a somewhat less common criticism of mixed-disability services, and contested in discussions of general services.

#### Autistic Adults' Concerns about Personal Aspects, Harm, and Safety Need Attention

Personal aspects were more common in responses from autistic adults than from parents/guardians. Parents/guardians also wrote about personal aspects, but these concerns become overshadowed by others when considering both responses together. They therefore merit further attention. Differences in the responses between autistic adults (more concern for harm/safety issues and personal aspects such as enjoyment and facing stereotyping) and parents/guardians relate to their different positionalities within services (first person vs. third person) and broader tensions between autistic self-advocacy and parent advocacy. Autistic respondents generally describe their first-person experiences with services as the primary service users. Parents/guardians, on the other hand, generally describe third-person experiences with services (the exception being support groups, which may additionally or exclusively include parents/guardians). Parents/guardians may not necessarily be representing the experiences of autistic people, although they may report on them. Parents/guardians often make important decisions about service use but are not the service users themselves. The perspectives of parents/guardians and autistic adults may not always be aligned, as is well documented in the social science and ethics literature [44] and described above by one autistic participant. Tensions between autistic adults and parents/guardians are especially prominent in conflicts between self-advocate-driven versus parent-and-professional-driven social movements [34]. These tensions are not inevitable, and autistic people and parents/guardians may often be aligned in daily life [37]. The strength of these tensions in social movements may also vary cross-culturally [45].

## Implications

The results of this study demonstrate a wide range of concerns that parents/guardians and autistic adults have when it comes to services for autistic people. The core issues unpacked in this discussion have implications for prospective service users and decision-makers, as well as for policy and practice.

With respect to inclusion, these results may provide a starting point for reflecting on and asking about views on and goals for inclusion. Prospective service users (or decision-makers) may therefore find it useful to ask themselves about their priorities and own definition of inclusion and to ask services about their vision of the relationship between clinical goals (such as social skills development) and inclusion. Some advocacy organizations put forth guiding questions, such as those listed in the Autistic Self Advocacy Network's "Start Here: a guide for parents/guardians of autistic kids" under the heading "How do I know if services are good or bad?" [46].

With respect to accessibility, these results suggest a concern for the lack of accessibility both of and within services, with some contested recognition of good accessibility within autism-specific services and some recognition of good accessibility of general services. These findings reinforce prior research identifying unmet service needs and calls for greater service availability. Non-autism-specific services can show their availability and openness to autistic participants by advertising in a diversity of places, including places that already reach autistic audiences, and by featuring diverse people (including diverse autistic people) in communications. They can draw on the strengths of autism-specific services to be "autism-friendly," for example, by creating environments with limited sensory input (sounds, lights, movement, etc.) for people who might enjoy meeting in such a place. Above all, in light of these results, service providers can ask potential service users about access needs, including both specific access issues mentioned herein and open-ended questions to elicit needs unique to the individual.

With respect to autistic adults' concerns, it is especially important for parents/guardians, service providers, and policymakers to ensure that these personal aspects are not overlooked when choosing and planning services for this often marginalized population. While clinical, societal, and interpersonal

reasons were more commonly discussed overall among respondents in our survey, several subthemes appeared more commonly among the group of autistic adults, including harm/safety issues, respect, and enjoyment. Many of these subthemes address the personal aspects of service preference. The perspectives of autistic adults are underrepresented, both within this study and within the broader scholarly literature and sociopolitical landscape. Although these subthemes may not have occurred as frequently, they remain particularly important in the context of this underrepresentation and warrant dedicated attention. It thus remains crucially important to avoid over-generalizations about service preferences.

## Limitations, Strengths, and Future Directions

Our recruitment strategy may have prioritized people who prefer autism-specific services. Although we tried to recruit from a range of places, it was easier to find autism-specific venues. Additionally, respondents who chose to take part in a study about autism might more strongly identify with autism than those who did not reply. Nonetheless, we obtained a large sample with strong buy-in in terms of quantity and depth of responses to the open-ended questions. We had broad inclusion criteria, allowing us to access a range of perspectives. We analyzed these responses in a rigorous way with two coders, a training period, and an arbitrator, offering a strong empirical contribution to the literature on autism services. While the respondents were generally highly responsive to open-ended questions, the depth of the qualitative analysis is limited by the fact that these data emerge from a larger mixed-methods study. These findings would benefit from in-depth exploration comparing different categories of services using fully qualitative methods.

## Conclusion

Scholars and activists debate whether autistic people should access autism-specific services or services that are more general/inclusive/mainstream in their approach. The perspectives of people who use these services (or make decisions about service use, i.e., parents/guardians) should inform this debate. In

this mixed-methods survey of autistic adults and parents/guardians of autistic people, we found that most respondents preferred autism-specific services, but nearly as many preferred different levels of autism-specificity for different service types. Analysis of open-ended responses reveals the reasoning underpinning preferences about autism-specificity. Clinical reasons, such as the service helping in general or with specific needs, or the preparedness of staff, were indeed the chief reasons for preferring any type of service, especially autism-specific services. Other common reasons were societal (inclusion) and interpersonal (good relationships with staff). These reasons do not represent two separate and opposing views (e.g., clinical/medical vs. social models), as it might appear at first glance. Rather, they interact in complex ways that go beyond reducing one to the other. All service categories have advantages and disadvantages, such that it may not be possible to say that autism-specific services are categorically better or not. Regardless of service category, prospective service users, providers, and policymakers should reflect on the meanings of and goals for inclusion, learn from the strengths of existing services where applicable, and remain mindful to personal concerns that might otherwise be overlooked. The key lesson that no service configuration can be ideal for everyone can guide service providers' attention to these details and open explicit communication about them to service users.

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**Authors' Contributions** M. Ariel Cascio conceived of the study and designed it with the supervision of Eric Racine. Cascio led the collection of data with the supervision of Racine. Cascio and Racine both made substantial contributions to data analysis and interpretation – Cascio as one of two coders and Racine as code tie-breaker, and both involved in the iterative interpretive process. Both authors drafted and critically revised this manuscript, approve this version of the manuscript to be submitted and published, and agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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**Availability of Data and Material** Due to the nature of this research, participants of this study did not agree for their data to be shared publicly, so data are not available.

**Code Availability** N/A.

**Declarations**

**Ethics Approval** The Research Ethics Committee of the Institut de recherches cliniques de Montréal approved this study.

**Consent to Participate** Respondents provided informed consent online.

**Consent for Publication** No identifying details are published.

**Conflicts of Interest/Competing interests** The authors report no conflicts of interest.

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