

## RESEARCH ARTICLE

# Autism service preferences of parents/guardians and autistic adults in five countries

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## Abstract

Scholars and activists debate whether people on the autism spectrum should access autism-specific services or general/inclusive/mainstream services. This article presents quantitative results from a mixed-methods survey of autistic adults and parents/guardians of autistic people in Canada, France, Germany, Italy, and the United States. Respondents reported categories of services used (autism-specific, mixed-disability, or general/inclusive/mainstream), satisfaction, and overall service preference. Most respondents preferred autism-specific services, followed by different categories of services for different service types. Demographic factors had little influence on overall service preferences. No significant differences were found between adults' and parents/guardians' overall service preferences. For parents/guardians, using autism-specific services was associated with a preference for autism-specific services. There were significant associations between the services respondents reported having previously used and their overall service preference. Parents/guardians in Italy and France reported lower satisfaction with many services. These results suggest that a preference for autism-specific services pervades different groups. While most respondents did endorse autism-specific services, the strong secondary preference for different service categories encourages providers and policy makers to attend to diverse needs. While satisfaction was generally middling to high, there remain areas for improvement, especially in general job training services. General services can use a Universal Design approach and collaborate with autism-specific and mixed-disability services to increase accessibility to diverse populations. The influence of previous service use on preferences suggests that providers can leverage strengths of existing services, leverage and create connections, and ask users about previous experiences to better address their expectations.

## Lay Summary

This study asked autistic adults and parents/guardians of autistic people what they think about autism services. Most parents/guardians and adults liked services that focus on autism, but many parents/guardians and adults liked them for some things and not others. All services can ask people about services they used in the past and learn from the strengths of good services through Universal Design and working with other services.

## KEYWORDS

adults, autism, cross-national, parents, service preferences

## INTRODUCTION

Autistic people and their parents seek and engage with many types of health and human services. Some of these services may be autism-specific, while many are not. Both

parent advocacy groups and autistic self-advocates have argued in favor of autism-specific services. Some of these arguments are clinical—that autism-specific interventions are more effective or efficacious (Panerai et al., 2009; Perry, 2002; Shepherd & Waddell, 2015). Some

arguments are social—that autistic “neuro-separate” spaces created by and for autistic people allow autistic people to flourish without the pressures of a neurotypical society (Bertilsdotter Rosqvist et al., 2013). These neuro-separate spaces may also create a sense of safety for some autistic people, due to receiving understanding and acceptance, being free from neurotypical social expectations, and meeting sensory needs (Ryan & Räisänen, 2008). Notably, not all (or even most) autism-specific spaces are autistic neuro-separate spaces; many autism-specific spaces aim to be for autistic people, but are run or created by non-autistic people. Other advocacy stances oppose diagnostic specificity, seen in calls for inclusive education (Slee, 2001). Some types of cross-disability activism have been contrasted with the greater diagnostic specificity of a “biosociality” approach (Block et al., 2011; Hughes, 2009), and general goals of inclusion and integration. Clinically, several studies have investigated which approach is most effective at various indicators, particularly in the case of inclusive education, with mixed results (Carter et al., 2008; Conaughton et al., 2017; Locke et al., 2010; Lorenz et al., 2016; Orsmond et al., 2004; Owen-DeSchryver et al., 2008; Panerai et al., 2009; Russell & McCloskey, 2016). Ethically, the structuring of these environments raises questions about the most just way to organize services in a neurologically diverse society.

This study contributes to debates about autism-specific services by investigating the preferences of people who access them. Previous scholarship suggests that autistic people and parents may have different perspectives on autism-services and autism-specificity. The “autistic community” (of self-advocates) and the “autism community” (of parents and professional advocates) often differ in their stance on specific interventions, research goals, and politics, especially in North America (Carey et al., 2019). The autistic community may use more social arguments (social model of disability), whereas the autism community may use more clinical arguments for autism-specificity (medical model of disability). Both movements may use biologically rooted notions of different kinds of minds. Despite these tensions at the level of social movements, parents and autistic people “on the ground” may in fact share similar goals, and parents may draw from both medical and social models of disability (Cascio, 2012; Friend, 2014). It is therefore important to directly investigate the differences between parents and autistic people. We invited both adults on the autism spectrum and parents of people with autism of any age to complete (largely similar) surveys on these services.

## RESEARCH SETTINGS

This project takes a cross-national approach to understanding autism service preferences and debates about

autism-specificity. While the autistic community and autism community are more at odds in North America, self-advocacy groups and parent advocacy groups are more aligned in other regions (Cascio, 2020). The United States and Canada follow the North American model described above. In Germany, scholars have documented similar tensions (Jongsma et al., 2017; Raz et al., 2018). In France, self-advocacy and parent groups have been more aligned in their goals and perspectives, particularly in rejecting psychoanalysis and ensuring access to services (Chamak, 2008), although self-advocacy groups have distanced themselves from parent groups more recently (Chamak & Bonniau, 2013). Similarly in Italy, self-advocacy groups partner more with parent groups and professionals (Cascio, 2015; Cascio et al., 2018; see also Cola & Crocetti, 2011).

These contrasts are in line with broader social science theories about regional differences in “Western biomedicine” (Gaines, 1982). German and North American psychiatry draw heavily from biological approaches—especially Kraepelinian psychiatry (Gaines, 1982). France and Italy, on the other hand, see a stronger influence of psychoanalysis and tensions between psychoanalysis and other camps regarding autism specifically (Chamak, 2008; Feinstein, 2011). Even these regional groupings may be too broad, as there are important differences in service preferences, advocacy, and activism even between the United States and Canada (Baker & Steuernagel, 2009). We therefore investigate differences between each of the five countries rather than grouping them by region. Nevertheless, our choice of countries was theoretically driven by these regional studies. This choice was also driven by the practical possibility of collaboration with colleagues who could contribute to translation and recruitment in various languages.

## METHODS

The aims of this study included understanding the preferences of people with autism and their families with respect to integrated, mixed disability, and autism-specific services; and identifying demographic and experiential factors that influence these preferences. This article focuses on statistical analyses of those factors; forthcoming papers will present qualitative results (Cascio & Racine, Accepted).

We designed an online survey to investigate service preferences. There were two versions: one for adults on the spectrum and one for parents/guardians of people with autism of any age. The survey was available in English, Italian, French, and German. It was developed in English; translated into Italian, French and German; verified by at least one other academic reader in each language; read by members of that language’s autism or autistic communities (parents or self-advocates) back-translated; and corrected.

The survey included both closed-ended and open-ended questions. Parents/guardians and adults on the spectrum provided similar demographic information. Parents/guardians were additionally asked to rate how knowledgeable they were about autism, how many children they had, and how many of their children were on the autism spectrum. Adults were additionally asked to indicate on a 7-point scale how much support they needed in daily life, and how much support their parents/guardians provided towards receiving appropriate services. Both surveys asked respondents to indicate their socioeconomic status via the MacArthur Ladder scale (Adler et al., 2007); adults on the spectrum were additionally asked their parents' social class.

Closed-ended questions explored whether or not participants had used services in eight different service types (as well as "another type of service"); and whether those services were autism-specific, mixed-disability, or general (Table 1). Service types were the same for both surveys, but for parents/guardians support groups included both those they and their children accessed. For each service category and type used, we asked respondents to rate

how happy (soddisfatto/a, satisfait, zufrieden) respondents were, on a 5-point Likert scale. We also asked which type of service respondents preferred overall, with the option of preferring different categories for different service types. Open-ended questions allowed respondents to elaborate on service use, evaluation, and overall preference answers; list the advantages and disadvantages of each service category; and provide final comments. These questions were the same for both respondent groups.

Two demographic questions posed particular difficulties due to the multi-national structure of the survey. First, education level was difficult to measure in a standardized way due to differences in educational systems: the German version differed from the others. We collapsed the education responses into three categories for analysis: less than secondary, completed secondary, and post-secondary. Those who listed their education as "other" (7 adults, 4 parents/guardians, and 32 eldest children) were excluded from analysis. Second, ethnicity was difficult to ask, especially in Italian and German. We used locally conventional categories of ethnicity or migration background. English and French options were White, Black, Latin American, Arabic, South Asian, Southeast Asian, West Asian/Middle Eastern, Filipino, Chinese, Korean, Japanese, Native American, Native Hawaiian, or Pacific Islander. Italian options were Romania, Albania, Morocco, China, Ukraine, the Philippines, India, Moldova, Bangladesh, and Egypt. German options were Turkish, Italian, Polish, and Russian. For analysis and reporting, we combined responses into "majority" (white/caucasien[ne], italiano, Deutsch) and minority (other responses, excluding "other" and "refused").

The English version of the survey is provided as Supplementary material S1.

**TABLE 1** Service type and category definitions. Terms used in this article are bolded.

Service type and category definitions
<i>Service types</i>
<b>Early intervention</b> services (before attending school). These might be classes or individual work with a therapist or teacher
Services at <b>school</b>
<b>Job training</b> services (for example, vocational rehabilitation)
<b>Social/recreational</b> services (things that you/they do for fun such as social clubs, camps, sports, games, theater, art, and so forth).
<b>Day</b> services (a place you/they go during the week that is not school or work, with staff and activities)
<b>Residential</b> services (staff-supported permanent or temporary living situations. It includes things like group homes and protected apartments. It does not include living with parents, spouse, or other family members, renting an apartment alone or with roommates, or owning a home or apartment alone or with roommates. It does include living in a college or university dormitory)
<b>Clinics</b> , hospitals, or doctor's offices for therapy, interventions, or other things that have to do with autism
<b>Support groups</b> (you or your children)
<b>Another</b> type or types of service
<i>Service categories</i>
<b>Autism-specific</b> : Made mostly for people with autism; most of the people who go there have autism; sometimes, the word autism is in the name.
<b>Mixed-disability</b> : 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
<b>General</b> : Made mostly for people without disabilities, but includes people with autism; sometimes called "inclusive," "integrated," or "mainstream."

## Data collection

The survey was available online from April to November 2017. Participants were recruited through research team networks and autism and disability resources identified online. We emailed an invitation to share the survey and a reminder to services, associations, support groups, schools, and listservs as well as posting it on our academic social media. We attempted to share our invitation with a wide range of service types. However, due to the nature of the question being about autism, autism-specific services are likely overrepresented (see limitations). Participants completed a consent form and had the opportunity to enter into a raffle for one of five 100CAD Amazon gift cards. Raffle entries were not linked to individual responses. Multiple entries were discouraged through IP limiting in each survey version. The study was approved by the Research Ethics Committee of the Institut de recherches cliniques de Montréal.

## Data analysis

In collaboration with a statistics consultant, we conducted correlations between continuous demographic variables and satisfaction; one-way ANOVAs between categorical demographic variables and satisfaction; chi-square tests between categorical variables and overall service preference; and odds ratios to compare overall service preference between respondent groups (adults with autism and parents/guardians). We investigated associations between satisfaction with services and the key demographic variables of parent/guardian age, sex, occupation, education, relationship status, and ethnicity; eldest child with autism age, sex, education (schooling completed), ethnicity, IEP usage, and additional reported diagnoses; adults' age, sex, occupation, education, IEP usage, additional reported diagnoses, religion, and relationship status. Sample sizes for parent/guardian religion, oldest child's occupation and marital status; and adults' ethnicity were too small to test (sampling cells less than 10). Other demographics are presented for descriptive purposes only. When sample sizes for one service category were below 10 for that demographic variable, associations were not tested. In the parent/guardian survey, this happened most often for job training and residential services, as well as mixed-disability and general support groups. In the adult survey, this happened with most early intervention, school, day, and residential services as well as autism-specific job training services and social/recreational services, and general support groups. For sample sizes that were small, but above 10, Tukey HSD post-hoc tests were used for multiple comparison analyses in the ANOVAs to account for the increased risk of type 1 statistical errors.

Analyses were conducted with IBM SPSS version 26.0 (IBM Corp., 2019).

## RESULTS

Responses from 699 parents/guardians and 132 adults on the spectrum were included in the quantitative analysis. Five responses from parents were excluded from quantitative analysis due to problems with certain demographic responses that inhibited data analysis. Full demographics are available upon request, with select demographics presented here (Table 2). There were a few significant differences between parent/guardian respondents in different countries. Significantly more parents/guardians in Italy were male ( $\chi^2(4) = 15.002, p = 0.005$ ; vs. Canada OR = 4.81, 95%CI: 1.82–12.67; vs. United States OR = 3.32, 95%CI: 1.57–7.05; vs. France OR = 2.63, 95%CI: 1.11–6.23; vs. Germany OR = 2.07, 95%CI: 0.95–4.49). Significantly more parents/guardians had lower levels of education ( $\chi^2(4) = 59.667, p = 0.0001$ , OR = ? CI = ?) in Italy (vs. Canada OR = 3.39, 95%CI: 1.56–7.38; vs. United States OR = 9.42, 95%CI: 4.18–

21.22; vs. France OR = 3.87, 95%CI: 1.69–8.84; vs. Germany OR = 1.09, 95%CI: 0.57–2.10) and Germany (vs. Canada OR = 3.11, 95%CI: 1.60–6.05; vs. United States OR = 8.62, 95%CI: 4.26–17.47; vs. France OR = 3.54, 95%CI: 1.72–7.29). Fewer fulltime workers responded ( $\chi^2(8) = 50.491, p = 0.0001$ ) in France (vs. Canada OR = 0.42, 95%CI: 0.23–0.74; vs. United States OR = 0.69, 95%CI: 0.42–1.14; vs. Italy OR = 0.66, 95%CI: 0.33–1.33; vs. Germany OR = 1.50, 95%CI: 0.85–2.65) and Germany (Canada OR = 0.28, 95%CI: 0.16–0.48; vs. United States OR = 0.46, 95%CI: 0.29–0.74; vs. Italy OR = 0.44, 95%CI: 0.22–0.87). There were significant differences in respondent age ( $F[4, 648] = 9.655, p < 0.001, \eta^2 = 0.056$ ). Respondents in Italy were significantly younger than respondents in other countries (vs. Canada, 7.5 years,  $p < 0.001$ , 95%CI = 3.76–11.27; vs. United States, 6.2 years,  $p < 0.001$ , 95%CI = 2.78–9.65; vs. France, 3.3 years,  $p = 0.19$ , 95%CI = -0.54 – 7.09; vs. Germany, 5.1 years,  $p < 0.001$ , 95%CI = 1.40–8.71). Respondents in Canada were additionally significantly older than respondents in France (4.2 years,  $p > 0.001$ , 95%CI = -7.39 to -1.09) and respondents in United States additionally significantly younger than respondents in France (-2.9 years,  $p = 0.004$ , 95%CI = -5.69 to -0.19). Sample sizes were too small to evaluate differences in ethnicity and religion. There were no significant differences between autistic adult respondents in different countries.

Odds ratios suggest that parents/guardians more frequently than adults (Table 3) used early intervention services (OR = 0.09, 95%CI: 0.05–0.15), services in school (OR = 0.48, 95%CI: 0.34–0.68), and day services (OR = 0.50, 95%CI: 0.31–0.82) of all types. Parents/guardians also more frequently used autism-specific day services (OR = 0.27, 95%CI: 0.11–0.68) and mixed-disability social/recreational services (OR = 0.55, 95%CI: 0.33–0.91). Autistic adults more frequently reported using any type of job training services (OR = 3.87, 95%CI: 2.62–5.71), residential services overall (OR = 2.74, 95%CI: 1.69–4.46) and general (OR = 6.47, 95%CI: 3.38–12.40), and general support groups (OR = 2.75, 95%CI: 1.37–5.52). "Other" service use is reported in this table, but other services are excluded from analysis due to vague and varying range of services under this label.

Little difference emerged between Likert scale ratings of happiness/satisfaction with services between parents/guardians and autistic adults in most categories (Figure 1). However, parents/guardians did report higher ratings for autism-specific school services, general social/recreational services, and both mixed-disability and general clinics than adults. Autistic adults had higher ratings for mixed-disability and general school services, and general day services than parents/guardians.

Most respondents in both groups indicated that they overall preferred autism-specific services; almost as many respondents in both groups indicated that they preferred

**TABLE 2** Respondent demographic information

Variable n (%) unless otherwise specified	Autistic adults (N = 132)	Parents/guardians (N = 699)	Parents/guardians' eldest child with autism (N = 699)	Variable	Autistic adults (N = 132)	Parents/guardians (N = 699)	Parents/guardians' eldest child with autism (N = 699)
Response language							
English	52 (39.4%)	316 (45.2%)	—	Marital status	72 (54.5%)	52 (7.4%)	653 (92.8%)
French	16 (12.1%)	172 (24.6%)	—	Single	15 (11.4%)	13 (1.9%)	5 (0.7%)
Italian	1 (0.8%)	71 (10.2%)	—	Dating (not living together)	9 (6.8%)	51 (7.3%)	3 (0.4%)
German	63 (47.7%)	140 (20.0%)	—	Dating (living together)	27 (20.5%)	490 (70.1%)	5 (0.7%)
Country				Married/marriage-like	8 (6.1%)	74 (10.6%)	1 (0.1%)
Canada	16 (2.3%)	120 (17.2%)	—	Divorced	0 (0.0%)	12 (1.7%)	0 (0.0%)
United States	34 (25.8%)	247 (35.3%)	—	Widowed	1 (0.8%)	32 (4.5%)	—
Italy	1 (0.8%)	61 (8.7%)	—	Did not answer	—	—	—
France	11 (8.3%)	109 (15.6%)	—	Diagnosis <sup>a</sup>	—	—	—
Germany	67 (50.8%)	143 (20.5%)	—	Autism Spectrum Disorder	40 (30.3%)	—	397 (56.4%)
Did not answer	3 (2.3%)	19 (2.7%)	—	Autism or Autistic Disorder	14 (10.6%)	—	136 (19.3%)
Age				Asperger's Syndrome	107 (81.1%)	—	191 (27.1%)
Mean [range]	37.20 [18–66]	44.77 [25–81]	13.52 [2–86]	Pervasive Developmental Disorder	2 (1.5%)	—	60 (8.5%)
				Pervasive Developmental Disorder - Not Otherwise Specified	2 (1.5%)	—	55 (7.8%)
Did not answer	5 (3.8%)	27 (3.8%)	11 (1.6%)	Atypical Autism	2 (1.5%)	—	28 (4.0%)
Sex				Other Diagnosis (Rett, Fragile X, Multiple Complex Developmental Disorder)	0 (0.0%)	—	12 (1.8%)
Female	59 (44.7%)	618 (88.4%)	133 (18.9%)	Self-Diagnosis	11 (8.3%)	—	1 (0.1%) by child's parent
Male	71 (53.8%)	76 (10.9%)	562 (80.4%)	Did not answer	0 (0.0%)	—	3 (0.4%)
Other	2 (1.5%)	0 (0.0%)	1 (0.1%)	Other	0 (0.0%)	—	29 (4.1%)
Did not answer	0 (0.0%)	5 (0.7%)	3 (0.4%)	Do not know	2 (1.5%)	—	3 (0.4%)
Ethnicity <sup>a</sup>				Additional DX?	—	—	—
White, Italian, or German	123 (93.2%)	580 (83.0%)	593 (84.3%)	Yes	66 (50.0%)	—	316 (45.2%)
Non-White, -Italian, or -German	10 (7.6%)	66 (9.4%)	84 (11.9%)	No	56 (42.4%)	—	360 (51.5%)
Other	10 (7.6%)	59 (8.4%)	61 (8.8%)	Did not answer	10 (7.6%)	—	20 (2.9%)
Did not answer	1 (0.8%)	25 (3.6%)	23 (3.3%)	School currently attending (students only)	—	—	—
Religion <sup>a</sup>				High school or below	4 (12.9%)	—	441 (63.1%)

(Continues)

TABLE 2 (Continued)

Variable n (%) unless otherwise specified	Autistic adults (N = 132)	Parents/guardians (N = 699)	Parents/guardians' eldest child with autism (N = 699)	Variable	Autistic adults (N = 132)	Parents/guardians (N = 699)	Parents/guardians' eldest child with autism (N = 699)
Christian	49 (39.4%)	385 (54.6%)	—	Vocational technical school	4 (12.9%)	—	14 (2.0%)
Atheist/Agnostic	60 (45.4%)	167 (23.8%)	—	University (undergraduate)	16 (51.6%)	—	15 (2.0%)
Other	26 (19.8%)	90 (12.6%)	—	University (graduate)	7 (22.6%)	—	4 (0.6%)
Did not answer	7 (5.3%)	77 (10.9%)	—	Did not answer	0 (0%)	—	38 (5.4%)
Occupation <sup>a</sup>				Had an IEP in school	—	—	—
Student	31 (23.5%)	23 (3.3%)	508 (72.2%)	Yes	31 (23.5%)	—	514 (73.5%)
Part-time worker	30 (22.7%)	176 (38.5%)	17 (2.4%)	No	92 (69.7%)	—	143 (20.5%)
Full-time worker	44 (33.3%)	271 (38.5%)	17 (2.4%)	I do not know	8 (6.1%)	—	29 (4.1%)
Looking for work	17 (12.9%)	24 (3.4%)	20 (2.8%)	Did not answer	1 (0.8%)	—	13 (1.9%)
Retired	2 (1.5%)	31 (4.4%)	1 (0.1%)	Parent Support	—	—	—
Disability benefits	27 (20.5%)	29 (4.1%)	96 (13.6%)	(Mean [range])	3.63 [1–7]	—	—
None of the above	9 (6.8%)	155 (22.0%)	60 (8.5%)	Did not answer	4.5%	—	—
Did not answer	1 (0.8%)	12 (1.7%)	5 (0.7%)	Knowledge of autism	—	—	—
School completed				Mean [range]	8.44 [1–11]	—	—
Less than secondary	6 (4.6%)	26 (3.7%)	546 (78.1%)	Did not answer	4 (0.6%)	—	—
Completed secondary	31 (23.5%)	75 (10.7%)	62 (8.9%)	Number of children	—	—	—
Post-secondary	88 (66.7%)	582 (83.3%)	45 (6.4%)	0	—	4 (0.6%)	—
Other (German)	7 (5.3%)	4 (0.6%)	32 (4.6%)	1	—	162 (23.2%)	—
Did not answer	0 (0%)	12 (1.7%)	14 (2%)	2	—	310 (44.3%)	—
Social class				3	—	131 (18.4%)	—
Mean [range]	4.93 [1–9]	5.98 [1–10]	—	4	—	51 (7.3%)	—
Did not answer	9 (6.8%)	40 (5.7%)	—	5	—	25 (3.6%)	—
Parent social class				6 or more	—	10 (1.4%)	—
(Mean [range])	5.81 [0–9]	—	—	Did not answer	—	6 (0.9%)	—
Did not answer	15 (11.4%)	—	—	Number of children ASD	—	—	—
Support level				1	—	619 (87.9%)	—
(Mean [range])	3.05 [1–7]	—	—	2	—	64 (9.1%)	—
Did not answer	7 (5.3%)	—	—	3	—	8 (1.1%)	—
				4	—	1 (0.1%)	—
				Did not answer	—	7 (1.0%)	—

Note: IEP: Individualized Education Plan/plan d'intervention personnalisée (PIP), un PAP Plan d'Accompagnement Personnalisé (PAP), ou un projet personnalisé de scolarisation (PPS)/piano educativo individualizzato (PEI)/individualisierten Bildungsplan (IBP); 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.

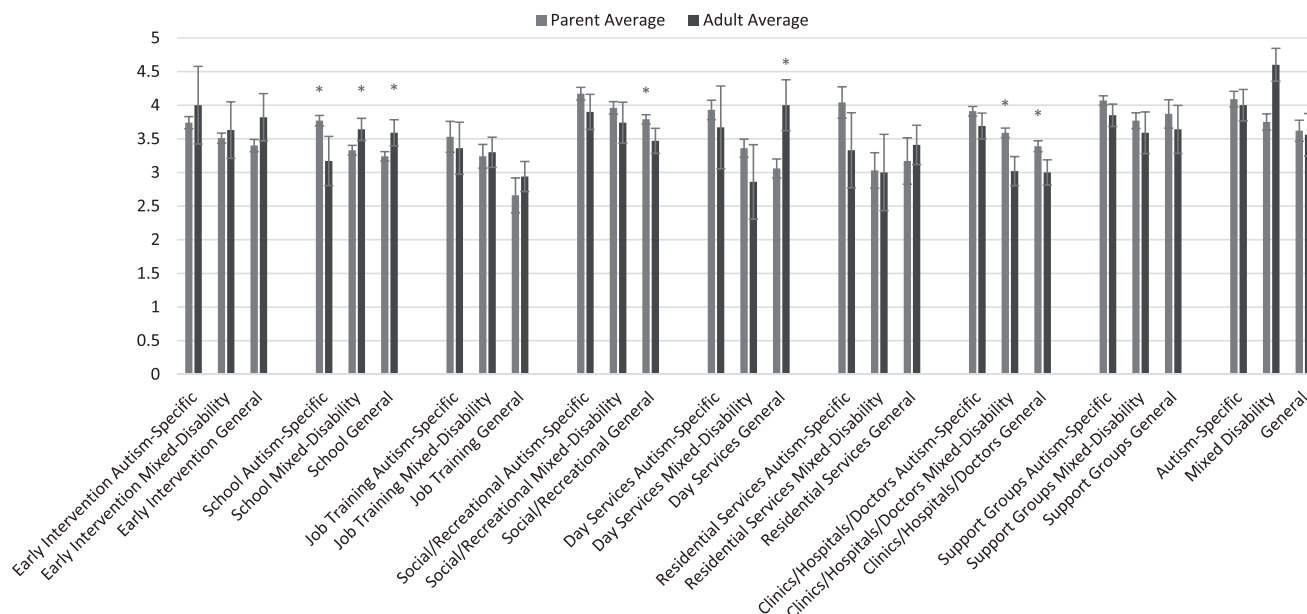
<sup>a</sup>More than one response could be selected.

TABLE 3 Service usage

	Total		Autism specific		Mixed disability		General	
	Adults	Parents/Guardians	Adults	Parents/Guardians	Adults	Parents/Guardians	Adults	Parents/Guardians
Early intervention	17 (12.9%) OR = 0.09, 95%CI: 0.05-0.15	433 (61.9%)	3 (2.3%) OR = 0.07, 95%CI: 0.02-0.21	242 (34.6%)	8 (6.1%) OR = 0.15, 95%CI: 0.07-0.31	287 (41.1%)	11 (8.3%) OR = 0.29, 95%CI: 0.15-0.54	204 (29.2%)
Service in School	46 (34.8%) OR = 0.48, 95%CI: 0.34-0.68	509 (72.8%)	12 (9.1%) OR = 0.23, 95%CI: 0.13-0.42	276 (39.5%)	36 (27.3%) OR = 0.56, 95%CI: 0.38-0.83	338 (48.4%)	27 (20.5%) OR = 0.50, 95%CI: 0.32-0.78	285 (40.8%)
Job training	57 (43.2%) OR = 3.87, 95%CI: 2.62-5.71	78 (11.2%)	14 (10.6%) OR = 2.00, 95%CI: 1.05-3.81	37 (5.3%)	33 (25.0%) OR = 3.18, 95%CI: 1.99-5.08	55 (7.9%)	33 (25.0%) OR = 6.03, 95%CI: 3.53-10.26	29 (4.1%)
Social recreation	81 (61.4%) OR = 0.95, 95%CI: 0.70-1.29	451 (64.5%)	20 (15.2%) OR = 0.62, 95%CI: 0.37-1.01	172 (24.6%)	19 (14.4%) OR = 0.55, 95%CI: 0.33-0.91	184 (26.3%)	62 (47.0%) OR = 1.11, 95%CI: 0.79-1.54	297 (42.5%)
Day services	21 (15.9%) OR = 0.50, 95%CI: 0.31-0.82	221 (31.6%)	5 (3.8%) OR = 0.27, 95%CI: 0.11-0.68	98 (14.0%)	7 (5.3%) OR = 0.31, 95%CI: 0.14-0.68	119 (17.0%)	7 (5.3%) OR = 0.36, 95%CI: 0.16-0.79	103 (14.7%)
Residential services	29 (22.0%) OR = 2.74, 95%CI: 1.69-4.46	56 (8.0%)	6 (4.5%) OR = 1.13, 95%CI: 0.46-2.79	28 (4.0%)	8 (6.1%) OR = 1.32, 95%CI: 0.60-2.94	32 (4.6%)	22 (16.7%) OR = 6.47, 95%CI: 3.38-12.40	18 (2.6%)
Clinics, hospitals, or doctors	88 (66.7%) OR = 0.92, 95%CI: 0.69-1.24	505 (72.2%)	54 (40.9%) OR = 0.90, 95%CI: 0.64-1.27	317 (45.4%)	48 (36.4%) OR = 0.76, 95%CI: 0.53-1.08	336 (48.1%)	61 (46.2%) OR = 1.25, 95%CI: 0.89-1.74	259 (37.1%)
Support group	62 (47.0%) OR = 1.13, 95%CI: 0.81-1.57	291 (41.6%)	54 (40.9%) OR = 1.11, 95%CI: 0.79-1.57	257 (36.8%)	17 (12.9%) OR = 0.82, 95%CI: 0.47-1.41	110 (15.7%)	13 (9.8%) OR = 2.75, 95%CI: 1.37-5.52	25 (3.6%)
Other services	52 (39.4%) OR = 1.36, 95%CI: 0.95-1.95	202 (28.9%)	15 (11.4%) OR = 0.83, 95%CI: 0.47-1.47	96 (13.7%)	5 (3.8%) OR = 0.25, 95%CI: 0.10-0.62	107 (15.3%)	16 (12.1%) OR = 1.10, 95%CI: 0.62-1.95	77 (11.0%)

Note: 95%CI that do not include 1.00 denote a significant OR. Abbreviations: CI, confidence interval; OR, odds ratio.

Satisfaction Levels of Parents and Adults by Service Type and Category



**FIGURE 1** Satisfaction level of parents/guardians and adults by service. Average satisfaction ratings (on a 5-point Likert Scale) from each group for each service type and category combination. Bars indicate standard error of the mean. “\*” indicates non-overlapping error bars suggest difference between parent/guardian and adult respondent groups

**TABLE 4** Correlations between age and service satisfaction

Service type service category	Parent/guardian age	Eldest child with autism age	Service type service category	Parent/guardian age	Eldest child with autism age
<i>Early intervention</i>			<i>Day</i>		
Autism-specific	0.084	-0.113	Autism-specific	-0.069	-0.158
Mixed disability	-0.068	-0.031	Mixed disability	-0.194*	-0.328***
General	-0.178*	-0.201**	General	-0.018	-0.101
<i>School</i>			<i>Residential</i>		
Autism-specific	-0.076	-0.033	Autism-specific	-0.127	0.047
Mixed disability	-0.162**	-0.099	Mixed disability	-0.627***	-0.560***
General	-0.148**	-0.151**	General	-0.487*	-0.330
<i>Job training</i>			<i>Clinics</i>		
Autism-specific	-0.117	-0.183	Autism-specific	-0.167**	-0.057
Mixed disability	-0.309*	-0.323*	Mixed disability	-0.167**	-0.136*
General	-0.422*	-0.292	General	-0.071	-0.100
<i>Social/recreational</i>			<i>Support groups</i>		
Autism-specific	-0.138	-0.152*	Autism-specific	-0.057	0.013
Mixed disability	-0.179*	-0.175*	Mixed disability	-0.157	-0.148
General	-0.058	-0.015	General	-0.607**	-0.541**

\* $p < 0.05$ . \*\* $p < 0.01$ . \*\*\* $p < 0.001$  (2-tailed test of significance).

different categories of services (i.e., autism-specific, mixed disability, or general) for different services types (i.e., early intervention, school, job training, etc.). Responding to the direct question about overall service preferences, 50.4% of parents/guardians selected autism-specific, 32.9% different categories for different service

types, 10.2% mixed-disability services, 4.3% general/inclusive/mainstream services, and 2.3% declined to answer. Among autistic adults, 41.7% selected autism-specific, 37.1% different categories for different service types, 6.8% general/inclusive/mainstream, and 6.1% mixed-disability; 8.3% declined to answer.



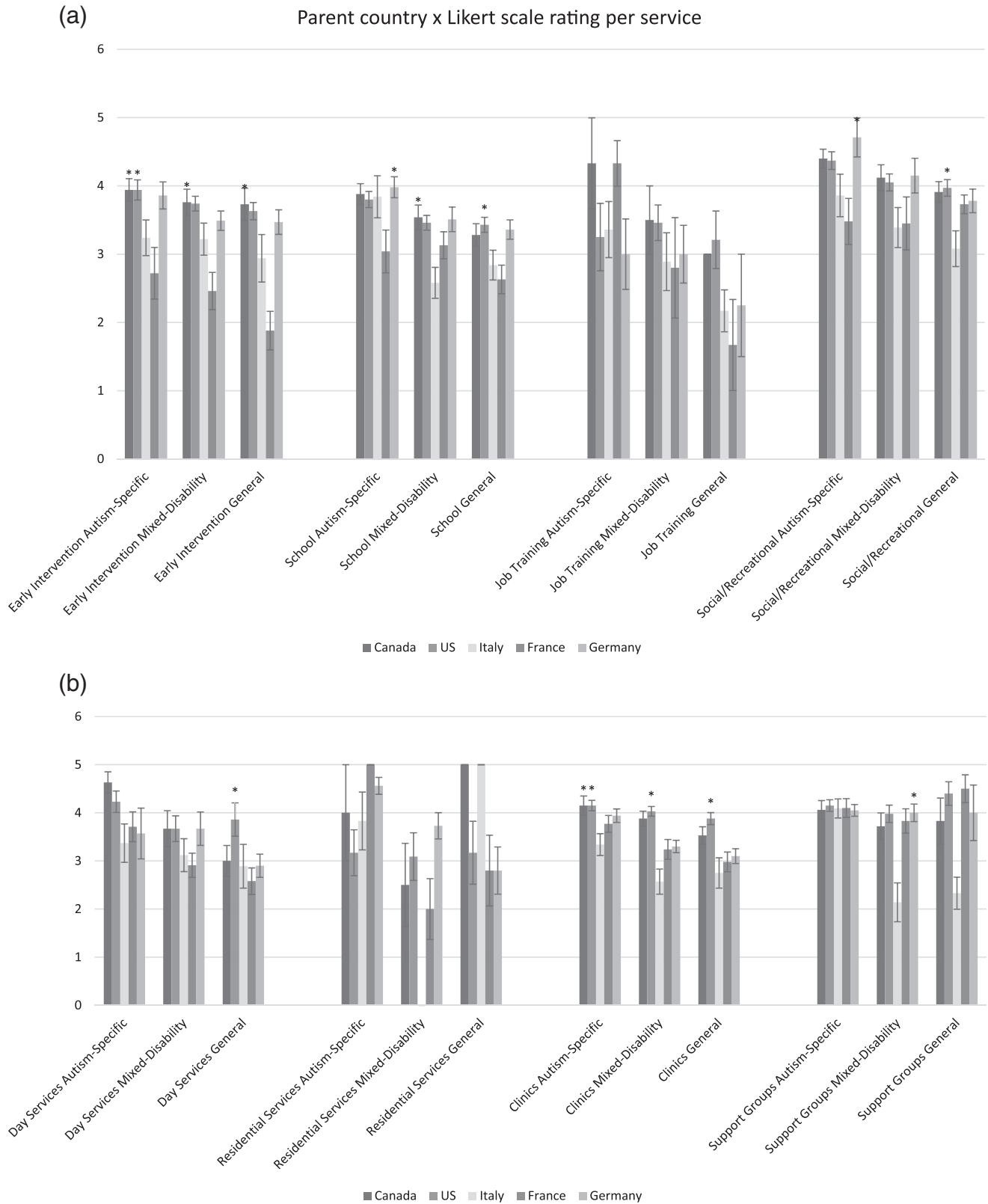
## Associations between demographics and service satisfaction

Age was a significant factor (Table 4). Across several service types and categories, satisfaction was higher in younger parents/guardians and in parents/guardians with younger children. Other associations appeared only in specific service type and category combinations. Male parents were more satisfied with autism-specific services in school ( $F[1, 275] = 5.725, p = 0.017, \eta^2 = 0.020$ ). Parent/guardian occupation was significantly associated with satisfaction with autism-specific services in schools ( $F[2, 233] = 3.553, p = 0.030, \eta^2 = 0.030$ ). A Tukey post-hoc showed that respondents who selected “none” reported lower satisfaction than full-time workers ( $p = 0.029, 95\%CI: -1.00$  to  $-0.04$ ). Due to small sample sizes, other occupation categories were excluded from this analysis. Parents/guardians reporting a post-secondary education were more satisfied with both general social/recreational services ( $F[1, 289] = 5.448, p = 0.020, \eta^2 = 0.019$ ) and mixed-disability clinics ( $F[1, 327] = 4.828, p = 0.029, \eta^2 = 0.015$ ) than parents/guardians with less than a post-secondary education. Education level of oldest child with autism was significantly associated with parent satisfaction with mixed-disability day services ( $F[2, 108] = 7.440, p = 0.001, \eta^2 = 0.121$ ). A Tukey post-hoc test showed that parents/guardians whose oldest child with autism had completed secondary education were significantly less satisfied than those whose oldest child had completed less than secondary ( $p = 0.001, 95\%CI: -2.63$  to  $-0.60$ ). Parents/guardians with minority children were significantly more satisfied with mixed-disability clinics, and so forth, than parents with children in the ethnic/national majority of their country ( $F[1, 275] = 6.204, p = 0.013, \eta^2 = 0.022$ ). Parents/guardians whose oldest child with autism had an IEP in school were significantly more satisfied with several services: mixed-disability ( $F[1, 265] = 4.507, p = 0.035, \eta^2 = 0.017$ ) and general ( $F[1, 190] = 6.516, p = 0.011, \eta^2 = 0.033$ ) early intervention services, mixed-disability school services ( $F[1, 327] = 8.444, p = 0.004, \eta^2 = 0.025$ ), autism-specific ( $F[1, 169] = 8.760, p = 0.004, \eta^2 = 0.049$ ) and general social/recreational services ( $F[1, 278] = 10.783, p = 0.001, \eta^2 = 0.037$ ). Parents/guardians who reported additional diagnoses for their oldest child with autism were significantly more satisfied with autism-specific ( $F(1, 304) = 4.102, p = 0.044, \eta^2 = 0.013$ ) and mixed-disability ( $F(1, 324) = 4.844, p = 0.028, \eta^2 = 0.015$ ) clinics, as well as general support groups ( $F(1, 19) = 4.934, p = 0.039, \eta^2 = 0.206$ ). They were also more likely to use services at school ( $\chi^2(1) = 7.711, p = 0.005, OR = 1.64, 95\%CI = 1.16$ – $2.34$ ), clinics ( $\chi^2(1) = 6.870, p = 0.009, OR = 1.59, 95\%CI = 1.12$ – $2.24$ ), and support groups ( $\chi^2(1) = 5.772, p = 0.016, OR = 1.46, 95\%CI = 1.07$ – $1.98$ ) and mixed disability early intervention ( $\chi^2(1) = 4.445, p = 0.035, OR = 1.56, 95\%CI = 1.03$ – $2.37$ ) and job training ( $\chi^2$

(1) = 5.058,  $p = 0.025, OR = 3.50, 95\%CI = 1.14$ – $10.76$ ), and less likely to use autism-specific early intervention ( $\chi^2(1) = 15.904, p = 0.001, OR = 0.45, 95\%CI = 0.31$ – $0.67$ ) or residential services ( $\chi^2(1) = 6.623, p = 0.010, OR = 0.23, 95\%CI = 0.08$ – $0.73$ ).

We also investigated cross-national differences (Figure 2a,b). There were significant differences between groups in satisfaction with autism-specific ( $F[4, 229] = 4.380, p = 0.002, \eta^2 = 0.071$ ), mixed-disability ( $F[4, 269] = 6.838, p < 0.001, \eta^2 = 0.092$ ), and general ( $F[4, 189] = 8.611, p = 0.0001, \eta^2 = 0.154$ ) early intervention; autism-specific ( $F[4, 271] = 2.643, p = 0.034, \eta^2 = 0.038$ ), mixed-disability ( $F[4, 327] = 4.036, p = 0.003, \eta^2 = 0.047$ ), and general ( $F[4, 306] = 3.972, p = 0.004, \eta^2 = 0.049$ ) school services; autism-specific ( $F[4, 164] = 3.749, p = 0.006, \eta^2 = 0.084$ ) and general ( $F[4, 284] = 2.878, p = 0.023, \eta^2 = 0.039$ ) social/recreational services; general day services ( $F[4, 96] = 2.561, p = 0.043, \eta^2 = 0.096$ ); autism-specific ( $F[4, 301] = 3.827, p = 0.005, \eta^2 = 0.048$ ), mixed-disability ( $F[4, 323] = 12.367, p < 0.0001, \eta^2 = 0.133$ ), and general ( $F[4, 247] = 6.990, p < 0.0001, \eta^2 = 0.102$ ) clinics; and mixed-disability support groups ( $F[4, 104] = 3.881, p = 0.006, \eta^2 = 0.130$ ). Sample sizes of users of job training ( $n = 78; n = 37$  autism-specific,  $n = 55$  mixed-disability,  $n = 29$  general) and residential services ( $n = 56; n = 28$  autism-specific,  $n = 32$  mixed-disability,  $n = 18$  general) were too small to test for significant differences by respondent country.

Tukey post-hoc tests showed that parents/guardians in France and Italy had significantly lower satisfaction scores on most types of services overall. Respondents from France reported lower satisfaction than Canada, the United States, and Germany for early intervention that was autism-specific [ $p = 0.008$  vs. Canada ( $95\%CI: -2.21$  to  $-0.22$ ),  $p = 0.006$  vs. United States ( $95\%CI: -2.19$  to  $-0.25$ ),  $p = 0.031$  vs. Germany ( $95\%CI: -2.22$  to  $-0.07$ )], mixed-disability [ $p < 0.0001$  vs. Canada ( $95\%CI: -2.10$  to  $-0.49$ ),  $p < 0.0001$  vs. United States ( $95\%CI: -1.99$  to  $-0.56$ ),  $p = 0.003$  vs. Germany ( $95\%CI: -1.81$  to  $-0.25$ )], and general [ $p < 0.0001$  vs. Canada ( $95\%CI: -2.87$  to  $-0.83$ ),  $p < 0.0001$  vs. United States ( $95\%CI: -2.64$  to  $-0.86$ ),  $p < 0.0001$  vs. Germany ( $95\%CI: -2.54$  to  $-0.62$ )]; as well as autism-specific school services [ $p = 0.038$  vs. Canada ( $95\%CI: -1.66$  to  $-0.03$ ),  $p = 0.043$  vs. United States ( $95\%CI: -1.51$  to  $-0.01$ ),  $p = 0.024$  vs. Germany ( $95\%CI: -1.80$  to  $-0.08$ )]. Respondents from France reported lower satisfaction with general school services than respondents from the United States [ $p = 0.008, 95\%CI: -1.47$  to  $-0.14$ ] and Germany ( $p = 0.048, 95\%CI: -1.47$  to  $0$ ). They reported lower satisfaction with autism-specific social/recreational services than respondents from Canada ( $p = 0.016, 95\%CI: -1.72$  to  $-0.12$ ) and the United States ( $p = 0.015, 95\%CI: -1.66$  to  $-0.12$ ). They reported lower satisfaction than respondents in the United States with general day services ( $p = 0.023, 95\%CI: -2.43$  to  $-0.12$ ), mixed-



**FIGURE 2** (a) Satisfaction level of parents/guardians by country and service type. (b) Satisfaction level of parents/guardians by country and service type (continued). Average satisfaction ratings (on a 5-point Likert Scale) from each group for each service type and category combination. Bars indicate standard error of the mean. “\*\*” indicates country with statistically significant highest Likert scale rating for that service type. Refer to text for specific statistical test values

disability clinics ( $p = 0.001$ , 95%CI:  $-1.33$  to  $-0.25$ ), and general clinics ( $p = 0.001$ , 95%CI:  $-1.51$  to  $-0.30$ ).

Respondents from Italy reported lower satisfaction than respondents in Canada, the United States, and Germany with mixed-disability school services [ $p = 0.008$  vs. Canada (95%CI:  $-1.73$  to  $-0.17$ ),  $p = 0.004$  vs. United States (95%CI:  $-1.55$  to  $-0.20$ ),  $p = 0.017$  vs. Germany (95%CI:  $-1.75$  to  $-0.11$ )] and clinics [ $p < 0.0001$  vs. Canada (95%CI:  $-2.08$  to  $-0.54$ ),  $p < 0.0001$  vs. United States (95%CI:  $-2.14$  to  $-0.79$ ),  $p < 0.0001$  vs. Germany (95%CI:  $-1.45$  to  $-0.01$ )]. They reported lower satisfaction than respondents in Canada and United States for general social/recreational services [ $p = 0.031$  vs. Canada (95%CI:  $-1.61$  to  $-0.05$ ),  $p = 0.011$  vs. United States (95%CI:  $-1.62$  to  $-0.14$ )] and autism-specific clinics [ $p = 0.035$  vs. Canada (95%CI:  $-1.58$  to  $-0.04$ ),  $p = 0.003$  vs. United States (95%CI:  $-1.41$  to  $-0.20$ )]. They also reported lower satisfaction with general clinics than respondents in the United States ( $p = 0.003$ , 95%CI:  $-1.98$  to  $-0.29$ ).

There were often no statistically significant differences between respondents in France and Italy. However, respondents in France did report being significantly more satisfied with mixed-disability support groups than respondents in Italy ( $p = 0.008$ , 95%CI:  $0.32$ – $3.05$ ). The Tukey post-hoc test also showed a few significant differences in responses from Germany. Respondents in Germany reported significantly lower satisfaction with mixed-disability ( $p = 0.001$ , 95%CI:  $-1.23$  to  $-0.24$ ) and general ( $p = 0.003$ , 95%CI:  $-1.39$  to  $-0.19$ ) clinics than respondents in the United States.

Among autistic adults, associations appeared only in a small number of service type and category combinations. There were no significant differences by country in adults' Likert scale ratings for mixed disability and general job training, general social recreational services, clinics of any category, or autism-specific support groups. Sample sizes for other service types and categories were too small to calculate. Occupation had a significant association with respondent satisfaction with autism-specific support groups ( $F[3, 35] = 4.327$ ,  $p = 0.011$ ,  $\eta^2 = 0.271$ ). A Tukey post-hoc test showed that respondents receiving disability benefits were significantly less satisfied than respondents who were working part-time ( $p = 0.005$ , 95%CI:  $-3.30$  to  $-0.47$ ). Due to small sample sizes, respondents who were looking for work, retired, or reported none of the above to the occupation question were excluded from this analysis. Respondents who completed post-secondary education were significantly more satisfied with clinics in all three categories (autism-specific  $F[1, 46] = 4.10$ ,  $p = 0.049$ ,  $\eta^2 = 0.082$ ; mixed-disability  $F(1, 41) = 6.492$ ,  $p = 0.015$ ,  $\eta^2 = 0.137$ ; general  $F(1, 52) = 6.495$ ,  $p = 0.014$ ,  $\eta^2 = 0.111$ ) than those who had completed only secondary education. The group with less than secondary education was excluded from analysis due to small sample size ( $n = 6$ ). Respondents who did not have an IEP were significantly more satisfied with

autism-specific job training than respondents who did ( $F[1, 11] = 5.592$ ,  $p = 0.037$ ,  $\eta^2 = 0.337$ ). Respondents who reported additional diagnoses had significantly lower happiness/satisfaction ratings than those who did not for general job training ( $F[1, 27] = 4.359$ ,  $p = 0.046$ ,  $\eta^2 = 0.139$ ), residential ( $F[1, 19] = 5.380$ ,  $p = 0.032$ ,  $\eta^2 = 0.221$ ), and support groups ( $F[1, 8] = 7.855$ ,  $p = 0.023$ ,  $\eta^2 = 0.495$ ); and for autism-specific clinics ( $F[1, 48] = 4.170$ ,  $p = 0.047$ ,  $\eta^2 = 0.080$ ). They were also significantly less likely to use autism-specific support groups ( $\chi^2(1) = 6.452$ ,  $p = 0.011$ ) although the odd ratios confidence interval (OR =  $0.82$ , 95%CI =  $0.24$ – $2.80$ ) included the null value of 1, indicating relative equality between groups. Religion was also significantly associated with satisfaction with mixed-disability school services. Respondents who indicated they were Christian were significantly more satisfied than respondents who reported being atheist/agnostic ( $p = 0.014$ , 95%CI:  $0.19$ – $1.95$ ) or having another religion ( $p = 0.009$ , 95%CI:  $0.28$ – $2.21$ ).

### Association between demographics and overall service preferences

There were very few significant associations between demographic factors and overall service preference. Male parents/guardians were significantly more likely to indicate a preference for autism-specific services ( $\chi^2(3) = 10.285$ ,  $p = 0.016$ ; OR =  $1.98$ , 95%CI:  $1.19$ – $3.29$ ). Cross-nationally, sample sizes were too small to identify significant differences for mixed-disability and general services, but parents in Italy were significantly more likely to prefer autism-specific services than parents/guardians in other countries ( $\chi^2(12) = 66.71$ ,  $p = 0.0001$ ; vs. Canada OR =  $2.57$ , 95%CI:  $1.29$ – $5.12$ ; vs. United States OR =  $3.48$ , 95%CI:  $1.84$ – $6.58$ ; vs. France OR =  $2.94$ , 95%CI:  $1.46$ – $5.93$ ; vs. Germany OR =  $3.41$ , 95%CI:  $1.746$ – $6.67$ ). Among adults with autism, there were no significant associations between demographic variables and overall service preference.

### Associations between service use and overall service preferences

No significant differences were found between autistic adults' and parents/guardians' responses to the overall service preferences question. Within each group, there were significant associations between the services respondents reported having previously used and their overall service preference. For parents/guardians, there was a significant association between the use of clinics and overall service preference ( $\chi^2(3) = 7.750$ ,  $p = 0.051$ ); parents/guardians who used any type of clinic were more likely to prefer autism-specific services (OR =  $1.35$ , 95%CI:  $0.96$ – $1.90$ ) and less likely to prefer mixed disability services

(OR = 0.65, 95%CI: 0.38–1.09) and general services (OR = 0.48, 95% CI: 0.23–1.00). Parents/guardians were significantly more likely to prefer autism-specific services when they had used autism-specific early intervention services ( $\chi^2(3) = 11.675, p = 0.009$ ; OR = 1.83, 95%CI: 1.25–2.70), social/recreational services ( $\chi^2(3) = 12.524, p = 0.006$ ; OR = 1.83, 95%CI: 1.24–2.7), day services ( $\chi^2(3) = 16.725, p = 0.001$ ; OR = 3.02, 95%CI: 1.73–5.27), and support groups ( $\chi^2(3) = 10.860, p = 0.013$ ; OR = 2.96, 95%CI: 1.39–6.30). Parents/guardians who used social/recreational services of any type, however, were less likely to prefer autism-specific services than those who did not ( $\chi^2(3) = 11.567, p = 0.009$ ; OR = 0.62, 95%CI: 0.45–0.85). Parents/guardians who used mixed-disability support groups were significantly ( $\chi^2(3) = 12.578, p = 0.006$ ) more likely to prefer mixed disability services (OR = 4.49, 95%CI: 1.68–11.96) and significantly less likely to prefer autism-specific services (OR = 0.62, 95%CI: 0.038–1.01). Parents/guardians who preferred autism-specific services had a significantly higher count of autism-specific services used than parents/guardians with other preferences ( $F[3, 679] = 7.673$ , Tukey HSD  $p < 0.0001$ , vs. mixed-disability services  $p = 0.001$ ; vs. general services  $p = 0.017$ ; vs. different categories for different services  $p = 0.042$ ).

Adults who used services in school were significantly more likely to prefer different categories for different services than those who did not ( $\chi^2(3) = 10.309, p = 0.016$ ; OR = 1.85, 95%CI: 0.87–3.94), as were adults who used job training ( $\chi^2(3) = 10.853, p = 0.013$ ; OR = 2.84, 95% CI: 1.34–6.03) and support groups ( $\chi^2(3) = 8.519, p = 0.036$ ; OR = 1.51, 95%CI: 0.72–3.17). However, the odd ratios confidence interval included the null value of 1 for school and support groups which indicates relative equality between groups. For many services, sample sizes were too small to calculate relationships between use of this service and overall service preference. There was no significant relationship between number of autism-specific services used and overall preference for autism-specific services.

## DISCUSSION

The general level of satisfaction with current services reported by respondents was middling to high, with scores of 3.00 or higher being on the positive side of the Likert scale for most services. Satisfaction scores were notably lower in general job training (parents/guardians and adults) and mixed-disability day services (adults only). The average satisfaction was above 4 on several points, including autism-specific support groups, residential services, and social/recreational groups (parents/guardians) as well as autism-specific early intervention (adults) and general day services (adults). These findings align with a French study (Rattaz et al., 2014) finding an average overall satisfaction for parents being 6.2 on a 10-point scale. A study

of opinions on early detection, diagnosis, and intervention services in a range of European Union countries, including Italy and France, concluded that parents had a lower opinion of these services than professionals for most metrics they used, averaging 4.6 on a scale from 1 to 7, highlighting delays in accessing services (Bejarano-Martín et al., 2020). Our results similarly demonstrate lower satisfaction among the parent/guardian respondent group for early intervention services (compared to autistic adults), reinforcing that this period poses a stressor for parents. Qualitative research has highlighted that parents may be positioned to manage, coordinate, and negotiate autism services in this period and beyond; these studies have been conducted especially in France (Chamak & Bonniau, 2018) but also elsewhere (Boursier et al., 2019; Hutton & Caron, 2005; Singh, 2016). Quantitative and qualitative studies both point to the need for greater parent support (Bejarano-Martín et al., 2020; Chamak & Bonniau, 2018; Molteni & Maggiolini, 2015). Our findings reinforce that need.

## Demographic and experiential influences

Very few demographic factors influenced overall service preference. There were no significant differences in service preferences between parents/guardians and adults with autism. There were a few demographic influences on service satisfaction, but more for parents than for adults. Satisfaction was higher for parents/guardians whose family members had an IEP, which could mean family members with higher levels of support needs. Notably a lot of this satisfaction was with general and mixed-disability services, suggesting they may be better received by parents/guardians of children with higher levels of support needs. Satisfaction was also higher in younger parents/guardians and parents/guardians with younger children. Bejarano-Martín and colleagues (Bejarano-Martín et al., 2020) analyzed responses by age at detection, diagnosis, and intervention, finding younger ages to be associated with greater satisfaction with early detection, diagnosis, and intervention services. In France, Rattaz et al. (2014) analyzed child's age, finding higher rates of dissatisfaction among parents of adolescents as compared to parents of children or adults. Our finding aligns, although we note that younger parents are also more satisfied. Thus, satisfaction may not depend on the child's age (or age of detection) alone, but also time period.

There was little influence of parent/guardian demographics on overall service preferences, but some influence of previous service use. Services that had a more "social" and less "therapeutic" quality (i.e., social/recreational, support groups) were particularly associated with corresponding preference for parents/guardians: parents/guardians who used autism-specific support groups were more likely to indicate a preference for autism-specific services and parents/guardians who used mixed-disability

support groups were more likely to indicate a preference for mixed-disability services, and parents/guardians who used social/recreational services of any type were less likely to prefer autism-specific services than those who did not. The strong influence of socially-oriented services on overall service preference could indicate an importance of the social domain in service preference that is often overlooked in favor of clinical aspects, yet important for supporting autistic people (Han et al., 2021). These findings do not indicate the precise relationship between having used autism-specific services and preferring them. People may have liked what experienced or sought what they liked. This question could be better answered with a focused follow-up study.

Use of more autism-specific services was not associated with a preference for autism-specific services. However, among autistic adults, use of several types of services was associated with a preference for different categories of services (i.e., autism-specific, mixed disability, or general) for different services types. The types of services associated with this preference—school, job training, and support groups—are broad, but school and job training are both aimed towards future preparation, suggesting that this type of preparation may introduce nuance. Subsequent qualitative analysis (Cascio & Racine, Accepted), shows a wide array of reasons for overall service preference.

## Comparing respondents in different countries

Some national differences emerged in this analysis. Most notably, parent/guardian respondents in Italy and France were more likely to have lower satisfaction across many service types and categories, despite respondents in Italy and France also being younger. France has been significantly influenced by psychoanalysis in the context of autism services (Chamak, 2008). Although this influence is present in Italy, especially in the northern regions geographically closer to France (Feinstein, 2011), the influence is not nearly as strong or as integrated into service provision (Cascio et al., 2018). In France, parent/guardian lack of satisfaction may be explained by frustration with psychoanalysis, described above. In Italy, parents/guardians may have lower satisfaction due to a lack of autism-specific expertise, also born out in the literature (Cascio, 2015). Open-ended responses, detailed in a forthcoming publication, also support these explanations.

## Implications

The results of this study have several implications for practices and policies about autism services. The relationship between younger parent age and higher satisfaction with services suggests that service satisfaction may overall be increasing with time, although our cross-sectional

study was not designed to answer this longitudinal question. Still, areas for improvement in autism services remain. Notably lower satisfaction ratings in general job training suggest a need for these services to increase accessibility for autistic service users. Indeed, unemployment and underemployment rates are high for autistic people in many countries (Hurley-Hanson et al., 2020). While there are autism-specific and mixed-disability job training and vocational rehabilitation services, autistic people may also access general services that support individuals' job searches, recruitment, interviewing, hiring, and human resources. The need for general services to be accessible to autistic people has received increasing attention, for example in the context of college and university career counseling (Dipeolu et al., 2015). One promising strategy to increase accessibility in general settings, including job training, is Universal Design. Universal Design, emerging from the field of architecture, "means that rather than designing your facility and services for the average user, you design them for people with a broad range of abilities, disabilities, ages, reading levels, learning styles, native languages, cultures, and other characteristics" (Burgstahler, 2018:2). Continuing with the example of career counseling services, Universal Design suggestions include outreach to students with disabilities; collaboration with programs that explicitly serve students with disabilities; training staff in responding to accommodation requests, and in talking with students about legal issues relevant to disability rights in the workplace; and providing information in multiple ways, for example, oral and written (Burgstahler, 2018). Applying these suggestions in the context of services for autistic people, general services could (in addition to the aforementioned) collaborate with autism-specific and mixed-disability services; minimize sensory barriers by reducing excess noise, light, and so forth; and present information visually in addition to orally and in writing.

Our findings suggest that previous service use is an important factor in overall service preference. Providers or policy makers looking to establish new services may therefore benefit from leveraging the strengths of existing services in the community. Existing services may also serve a role as "service brokers" (Fitzgerald et al., 2015), connecting people who make contact with their service to other potentially useful and welcoming services. Community members can also serve as brokers in this way (see Singh & Bunyak, 2019). New and existing services seeking to strengthen their relationships with people who may access them may draw on existing brokerage connections or seek to form new ones. Finally, these results suggests that it is important for service providers to ask existing or potential service users what previous services they have used, as a way to launch a broader conversation about expectations. This conversation can also reveal perceived strengths and brokerage connections that could be leveraged to further meet people's needs and connect them with a variety of helpful services.

## Limitations and strengths

Online surveys as used in this study limit participation to people with an internet connection. Education and ethnicity measures lack commensurability across language and country. Several subgroups lacked sufficient sample size to analyze, leaving several open questions that would benefit from more investigation. Recruitment may have been biased towards autism-specific channels because they were easier to locate and contact, although we did explicitly seek cross-disability and inclusive channels as well. Recruitment of volunteers inherently involves a self-selection bias where only respondents interested in taking a survey about autism respond. Respondents may identify more strongly with autism than non-respondents, and possibly be more likely to prefer autism-specific services. This study also evidences several strengths. We carefully defined our terms and allowed for broad reflection through open-ended questions. Including a broad range of diagnoses and allowing self-diagnosis minimized restrictions on participation, a strength in pursuing our aim to understand the everyday social and ethical dimensions of service preference. We also had community input at several stages that strengthened the work, even if we could not use all of it due to space constraints or to differences between languages.

## CONCLUSION

Debates are ongoing about the value of autism-specificity in services and the evidence supporting it. We undertook a large-scale cross-national survey study to investigate preferences for autism-specific, mixed disability, and general services. Both groups in all countries preferred autism-specific services. Overall few factors were associated with differences in this preference, suggesting the preference pervades different groups.

However, this majority preference is by no means unanimous. Although most respondents did prefer autism-specific services, this was followed by preference for different categories of services for different services types. It is important for service providers and policy makers to consider variations in autism service preferences and multiple perspectives, in order to understand the complex ethical and social contexts of service provision and service use. This study provides some indication of this variation, but future studies should explore it further by specifically targeting respondents who are less immersed in autism-specific services.

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## CONFLICT OF INTEREST

The authors declare no conflicts of interest.

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## SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

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